A descriptive phenomenological study exploring patient experiences of parenteral nutrition in an acute healthcare setting

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Abstract

Introduction: Parenteral nutrition (PN) is the intravenous administration of nutrition, required when the gastrointestinal tract is incapable of adequate nutrient absorption (NICE 2006). PN has higher levels of complications than other routes of feeding (Stewart et al. 2010) and restriction or modification of patients' oral intake is required to control gastrointestinal symptoms (Culkin, Gabe and Madden 2009). There is a lack of research investigating the experience of patients who require parenteral nutrition (PN) in acute care. Improving patient experiences of healthcare is a national priority following the Mid-Staffordshire Public Inquiry (Francis, 2013). The aim of this study was to explore the patient experiences of receiving PN in the acute healthcare setting.

Study Design: Descriptive phenomenology was the chosen methodology. Purposive sampling was used to recruit ten participants who had received PN for >7 days in an acute teaching hospital. In-depth interviews were conducted, which were audio-recorded. The interviews were transcribed verbatim and qualitatively analysed, guided by Colaizzi's (1978) approach.

Results: PN was universally considered positive by participants. It was 'life saving' and they felt it unlikely that they would have survived the hospital admission without it. Three core themes and seven subthemes were identified: 1) the altered relationship with food (subthemes: coping with the inability to eat 'normally' and loss of control over food-related decision making), 2) relationships with healthcare professionals (subthemes: competency, trust, coping with poor team working), 3) the need for patient centred care (subthemes: being heard, empowering the patient). The participants reported a profoundly altered relationship with food and eating whilst on PN due to the underlying intestinal failure. The organisation of nutritional

services were described as fragmented due to lack of coordination and poor communication. This resulted in confusion and anxiety for the participants due to the conflicting information provided, and affected their trust and confidence in their care. In addition, healthcare professionals frequently did not operate in a patient centred manner, failing to include patients in decision making regarding their nutritional treatment. This was particularly evident when several clinical teams were involved and when enteral nutrition was introduced. The participants were clear that they wished for their nutritional care to be controlled by the nutrition support team, who they described as experts and because they operated in a more patient centred manner.

Conclusion: Patient experiences of PN could be improved by nutrition support teams having greater autonomy regarding the provision of nutritional advice, better coordination and communication of nutritional care and by providing more support to patients on coping with the altered relationship with food.

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Abbreviations

CRBSI	Catheter Related Bloodstream Infection
CVC	Central Venous Catheter
FAACT	Functional Assessment of Anorexia/Cachexia Therapy [questionnaire]
GI	Gastrointestinal
HADS	Hospital Anxiety and Depression Score
HPN	Home Parenteral Nutrition
HPN-QOL	Home Parenteral Nutrition Quality of Life [questionnaire]
HRQOL	Health Related Quality of Life
IF	Intestinal Failure
IV	Intravenous
NBM	Nil by Mouth
NCEPOD	National Confidential Enquiry into Patient Outcome and Death
NHS	National Health Service
NICE	National Institute of Health and Clinical Excellence
NRES	National Research Ethics Service
NST	Nutrition Support Team
PINNT	Patient on Intravenous and Nasogastric Nutrition Therapy
PN	Parenteral Nutrition
QOL	Quality of Life
RCT	Randomised Controlled Trial
SF-36	Short Form 36 [Health Survey]
SGA	Subjective Global Assessment
TPN	Total Parenteral Nutrition
UK	United Kingdom
USA	United States of America

Chapter 1: Introduction

There is a scarcity of research investigating the experience of patients who require treatment with parenteral nutrition (PN)[1] in the acute healthcare setting. In the acute setting patients require urgent medical care or are recovering from surgery, resulting in often unstable, fluctuating medical states. The indications and treatment with PN are therefore different from patients who have chronic intestinal failure and receive PN in the homecare environment. PN is the intravenous (IV) administration of nutrients and water, through a central venous catheter[2], and should be considered in the presence of persisting intestinal failure (National Commissioning Group for Highly Specialised Services 2008, Nightingale 2001). Intestinal failure (IF) results from "obstruction, dysmotility, surgical resection, congenital defect or disease-associated loss of absorption and is characterised by the inability to maintain protein-energy, fluid, electrolyte or micronutrient balance" (O'Keefe et al. 2006: p6). PN is recommended where there is an inadequate or unsafe enteral feeding intake and a non-functioning, perforated or inaccessible gastrointestinal tract (NICE 2006). Three IF categories have been described by Shaffer (2002) (See Table 1). For each category the number of patients treated during 2013 at the NHS teaching hospital where this research study was undertaken is indicated.

From national data it has been estimated that 18 patients per million population require PN in hospital for >14 days - type 2 IF; although there are acknowledged large variations across England (National Commissioning Group for Highly Specialised Services 2008). These variations are primarily due to the differing levels of expertise NHS Trusts demonstrate in treating and caring for IF patients. Hospitals

[1] Often commonly described as '*total* parenteral nutrition' or 'TPN' however many patients do not receive nutrition from purely the parenteral route therefore the term 'parenteral nutrition' or 'PN' is referred to throughout for accuracy

[2] Commonly described by patients and healthcare professionals as 'feeding line' or 'line'

with significant gastroenterology, surgical and nutritional expertise will attract referrals from a wider geographical region and therefore record a higher proportion of IF patients. It should be noted that the estimated 18 patients per million population does not take into account the larger group of patients who require PN for less than 14 days (Type 1 IF).

Table 1: Types of Intestinal Failure (Shaffer 2002)

Historically PN is associated with higher rates of complications than other forms of artificial nutrition support e.g. catheter related bloodstream infection (CRBSI), metabolic abnormalities (Maroulis and Kalfarentzos 2000, Mazaki and Ebisawa 2008). The National Confidential Enquiry into Patient Outcome and Death (NCEPOD) national audit (Stewart et al. 2010) of the care of patients receiving PN in hospitals provided the most recent national complication rates (see Table 2). This audit found that 58% of patients experienced a complication whilst on PN (either central venous catheter related, metabolic or both).

Due to the complications associated with PN it is recommended that patients requiring PN be cared for by a multidisciplinary nutrition support team (NST) which includes core members with medical, dietetic, nursing and pharmacy expertise (Lennard-Jones 1992, NICE 2006, Powell-Tuck 2007). NSTs are currently established in 60% of United Kingdom (UK) hospitals (Russell and Elia 2012, Stewart et al. 2010) however the organisation, staffing and remit of these teams vary considerably (Stewart et al. 2010).

1.1 The Practice Based Issue

A nutrition support team has been in existence for 19 years in the organisation where the research was carried out. A critical incident and subsequent independent review of nutritional services resulted in changes to the practice and organisation of parenteral nutrition within the Trust. The review panel considered an index case which led to the invited review and investigation of the current state of nutritional services. The panel's broad recommendations focused on improving existing services and actions to reduce complications:

- Improvements to staffing levels and consultant leadership of the NST
- Introduction of a validated nutritional screening tool for identification of patients at risk of malnutrition in both the inpatient and outpatient setting
- Ensuring staff are able to attend teaching sessions on nutrition
- Ensuring robust referral mechanisms to nutritional services
- Having clear clinical governance arrangements for nutrition across the Trust

The specific changes that related to the PN component of nutritional services included:

- Ensuring regular audit of catheter related bloodstream infection rates

- Providing regular training to those who care for PN central venous catheters
- Restriction of PN to wards with suitable experience
- Ceasing out of hours provision of PN
- Stopping PN bag changes overnight
- PN prescriptions being signed by those with accepted training and competence

Although the reduction of complications should positively impact on the patient experience, no consideration of patient experience or satisfaction with the PN service was sought as part of the review process. Therefore issues that may be important to patients were not captured. Patients may experience numerous gastrointestinal symptoms depending on the gastrointestinal tract anatomy, underlying cause and likely duration of IF (Nightingale 2001). These symptoms could include high ostomy[3] outputs, severe diarrhoea, pain, nausea and vomiting. In order to avoid dehydration and under nutrition patients with IF are required to follow complex regimens of fluid, diet and medication and individualised advice and support is required (Culkin, Gabe and Madden 2009). The social impact of such regimens can be significant and pose numerous challenges for the patient (Winkler et al. 2010a). The researcher, a core member of a NST, identified that due to these issues, an in-depth understanding of the patients' experience is essential in the ongoing assessment and improvement of the services delivered by the NST. The aim of this study was, therefore, to explore the patient experience of receiving PN in the acute healthcare setting.

[3] Ostomy refers to a surgical opening of the bowel that is formed to permit the excretion of waste products from the body.

1.2 Patient Experiences of Hospital Care

The role of the patient in healthcare has evolved. Healthcare has "moved from a dominant paternalistic model of communication towards a pluralistic model which attempts to democratise decision making, share understanding and empower individuals" (Taylor 2009: p150). This shift in approach to healthcare, which now purports to place patients at the heart of care, has been influenced by:

- Trends in society: healthcare consumerism becoming increasingly important in healthcare policy, which was initially driven by the Thatcher government and influenced by the increasing prominence of patient groups (Department of Health and Social Security (DHSS) 1979, Mold 2011, Taylor 2009).
- Evolution of ethical principles: the paradigmatic approach has altered from a culture where beneficence[4] has been the dominant ethical principle to one in which autonomy[5] is valued as highly (Beauchamp and Childress 1989, Charles, Gafni and Whelan 1999, Taylor 2009).
- Evidence demonstrating that the communication style of healthcare professionals can affect patient concordance with treatment plans and influence both clinical and non-clinical outcomes (Britten et al. 2000, Nunes et al. 2009, Stavropoulou 2011).

The patient perspective of hospital care became an area of interest in the UK in 1969 as a result of a patient satisfaction survey conducted in England by the King's Fund (Raphael 1969). The survey was distributed to 2000 patients discharged from 10 hospitals and covered five key areas: the ward and its equipment, sanitary accommodation, meals, activities and care and overall contentment. Numerous

[4] Beneficence refers to actions taken for the benefit of the patient
[5] Autonomy in medicine refers to the patient being able to make an informed choice on the appropriate treatment plan based on being given the relevant information from healthcare professionals

surveys were carried out in the subsequent years with the 'social acceptability' of the care being received becoming an area of focus. Doll (1974) emphasised the importance of this kind of information to health professionals when he said: "Consider now the reaction of the patients and of their relatives and friends which, together with medical outcome, provides a measure of the quality of care that is offered" (p.309). In 2004 the Healthcare Commission was established to improve the quality of health care and since then has conducted regular patient surveys and service-user consultations on specific issues and these responsibilities have since been adopted by the Care Quality Commission (The Health Committee 2007).

The importance of understanding the patient experience in order that high quality care can be delivered is very topical in the current health policy literature. The Stafford Inquiry chaired by Robert Francis, Q.C. (Francis 2010a, Francis 2010b) raised many issues about the extent and nature of poor patient experience in an acute NHS Trust; in particular that complaints had not been addressed by the Trust and that the service was focused on governmental targets rather than the needs of the patient. This led to a larger public inquiry (Francis 2013) that gave rise to over 200 separate recommendations for improvements and emphasised that changes to service delivery should be informed by the experiences and needs of the service users.

Patient experience can be defined as "feedback from patients on 'what actually happened' in the course of receiving care or treatment, both objective facts and their subjective views of it" (Cornwell 2010: p7). The Department of Health (2005) defines the 'ideal' patient experience as "getting good treatment in a comfortable, caring and safe environment, delivered in a calm and reassuring way; having information to make choices, to feel confident and feel in control; being talked to and listened to as

an equal and being treated with honesty, respect and dignity" (Department of Health 2005: p7-8). Patients' experience in hospital is "shaped directly and indirectly by organisational and human factors interacting in complex ways at four levels: the individual member of staff, the team, and the clinical micro system, the institution and the wider health system" (Goodrich and Cornwell 2008: p44). The NHS outcomes framework 2015/2016 (Department of Health 2014) identifies the provision of a 'good experience' of care for patients as a central goal for the NHS making it one of the five core domains (Foot and Fitzsimons 2011). The increasing influence of the patient (or client) centred model of care is hindered by the diverse definitions adopted by different professional bodies - this impacts on how the concept is theorised and how this then influences practice (Cott 2006). The Picker Institute has focused on patient-centred care and their definition, which encompasses not only communication but wider system level aspects of care, is outlined in the Principles for Patient-Centred Care (Picker Institute 2012) (see Appendix 1). The NHS Patient Experience Framework is based on this work and provides detail concerning the nature of patient experience and how it can be measured (NICE 2012a) using defined quality standards (NICE 2012b) (see Appendix 2).

In summary, intestinal failure affects a relatively small number of patients, but its treatment intervention - parenteral nutrition, can result in significant complications (metabolic or central venous catheter related). The altered anatomy and/or physiological functioning of the gastrointestinal tract, along with the complex nutrition, fluid and medication regimens that patients' are required to follow to manage their condition, impact on the psychosocial state of the patient. The current focus on patient experience within healthcare, and the failure to address the

experience of service users, has resulted in patient experiences of parenteral nutrition being identified as a topic that warrants further exploration.

Chapter 2: Literature Review

2.1 The place of literature within phenomenological research

There is considerable debate about whether an in-depth literature review should be conducted prior to embarking on qualitative research, particularly in relation to phenomenological studies due to the potential influence that theory or prior research may have on the research process (Holloway 2005). However, demonstrating the gap in knowledge which the study seeks to address and justification of the research design was required as part of the ethical approval process, necessitating a review of the literature. Exploration and critique of the literature was also required in earlier assessed assignments submitted as a requirement of the professional doctorate programme. The process of bracketing, a core component of descriptive phenomenological research by which the researcher's prior knowledge and understanding of the topic of interest can be made explicit, will be discussed in the methodology and methods chapters. Additional literature will be explored to compare and contrast with the study findings in the results and discussion chapter.

2.2 Introduction

The aims of this literature review are twofold. Firstly, to critically review current research literature on patient experiences of acute healthcare and, in particular, patient experience of parenteral nutrition (PN). This will demonstrate the gap in knowledge and the original contribution to the field that this study makes. Secondly, to analyse methodological approaches used in research focused on patient experience to justify the qualitative approach chosen for this study.

Rigorous searches of major electronic databases (CINAHL, AMED, Academic Search Complete, Cochrane, Medline, National Institute for Health and Clinical

Excellence) were carried out using the following key search terms: *Patient, consumer, experience*, perspective*, perception*, satisfaction, opinion*, acute care, acute healthcare, hospital, method*, parenteral nutrition, parenteral feeding, PN, TPN, HPN.* The search terms were combined in numerous ways to extract articles for consideration, with additional articles identified through hand searching the reference lists of relevant articles. The articles obtained from the search were reviewed by the author and assessed against the inclusion and exclusion criteria (see Table 3).

The search was limited to the past 10 years due to the considerable changes to practice in both the NHS and the field of PN during this time. For example, PN practice has become more standardised, with emphasis on procedures for handling both PN and the central venous catheter (CVC) that it is administered through. There is also greater emphasis on appropriate patient selection and avoidance of feeding in excess of nutritional requirements to reduce the occurrence of metabolic complications (NICE 2006, Nightingale 2001).

Table 3: Inclusion and exclusion criteria

Inclusion Criteria	**Exclusion Criteria**
Adult patients >18 years	Paediatric or neonatal patients
Research papers published 2005 onwards	Studies related to the experience of a service or healthcare workers
Articles published in peer reviewed journals	Research papers relating to the development of tools for measuring outcome indicators
Patient experiences of parenteral nutrition	Studies related to intestinal transplantation
Patient experiences of nutrition	
Patient experiences of acute healthcare	
English language papers	

As a result of the literature search nineteen articles, reporting predominantly survey and qualitative studies along with a single randomised controlled study, were considered to inform an understanding of the patient experience and / or the choice

of qualitative research (Chambers, Hennessey and Powell-Tuck 2006, Dreesen et al. 2014a, Dreesen et al. 2014b, El Turabi et al. 2013, Elphick et al. 2009, Huisman-de Waal et al. 2006, Huisman-de Waal et al. 2011a, Huisman-de Waal et al. 2011b, Huisman-de Waal et al. 2011c, Naithani et al. 2008, Orrevall, Tishelman and Permert 2005, Oz, Theilla and Singer 2008, Persoon et al. 2005, Saunders, Abel and Lyratzopoulos 2014, Schliefert and Carey 2014, Tsang and Carey 2015, Winkler et al. 2010a, Winkler et al. 2010b, Ziebland, Evans and Toynbee 2011). In addition, one currently unpublished study (Baxter 2015) obtained from personal correspondence with the author was included as it was felt to contribute to the understanding of the current research within the field of PN. Details of the research articles discussed in this review, including study design, strengths and limitations are extracted and presented in Appendix 3.

The content of the literature review is divided into two sections:

- Patient experiences of hospital care
- Patient experiences of PN

The research papers are each described including the contribution they make to the understanding of the topic and compared to other literature where appropriate. Consideration is given to the methodological approaches used by these research studies, referring to the summary table in Appendix 3. The chapter will then conclude by justifying the choice of research approach for this study.

2.3 Patient experiences of hospital care

Patient experiences of hospital care are most frequently investigated using a survey research approach enabling large numbers of patients to be included, in order to identify trends and make comparisons between different organisations or patient

groups. An example of this type of approach is the *Cancer Patient Experience Survey* which has been conducted over the past four years to investigate the patient experience of cancer care at the one hundred and fifty three Trusts in England that provide adult cancer services (Quality Health 2014, Quality Health 2013, Department of Health 2012, Department of Health 2010). This national survey programme has demonstrated improved patient experience scores on forty-six (71.8%) of the questions between the first survey (Department of Health 2010) and the most recent survey (Quality Health 2014) with higher scores being correlated with the presence of a clinical nurse specialist for patient support. It was also been identified that patients with recurring cancer, and those acquiring a cancer diagnosis following emergency admission to hospital were less likely to give positive scores, identifying areas for improvement. A limitation of this survey research is that it was designed by an advisory group of healthcare professionals and there is a lack of detail about how the questionnaire was developed, whether any patient involvement was sought, or if any pilot tests were undertaken. Saunders, Abel and Lyratzopoulos (2014) undertook further statistical analysis of the 2011/2012 national survey data (Department of Health 2012) in order to explore why patients with cancer, treated in London hospitals, reported worse experiences of care compared to those treated in other English regions. The authors used mixed effects logistic regression to explore whether the difference could be explained by patient demographics (e.g. age, gender, ethnicity, cancer type) or due to the greater density of teaching hospitals in the region. However, despite this further analysis, it remained clear that patients treated in London hospitals had reported more negative care experiences that could not be explained by correlating any of the variables or the teaching hospital status. As a result, it was not possible to understand the mechanisms contributing to the

reported experience, but it was possible to rule out the impact of a number of factors. The authors proposed that the results could reflect either 1) differing expectations of care within the London region or, 2) poorer care quality leading to negative experiences, and they concluded that the latter is likely to be the main factor. Ultimately the secondary analysis of the survey data was unable to identify with any confidence *why* reported experiences were poorer and therefore did not provide the information required to inform service improvement initiatives. Similarly, El Turabi et al. (2013) conducted a secondary statistical analysis of the 2010 *National Cancer Patient Experience Survey* (Department of Health 2010) data focused on one specific question related to patient involvement in decision-making: *"Were you as involved in decisions about which treatment you would have as you wanted?"* The analysis identified that younger patients (aged 16-24), ethnic minorities and patients with rectal, ovarian, multiple myeloma and bladder cancers reported poorer experiences. This finding could assist clinicians in focusing their efforts on improving involvement of these groups in decision-making but does not address the reasons for the poorer experiences.

The degree to which patient surveys are able to assess *patient experience* is questionable and such surveys, in reality, frequently measure *patient satisfaction* instead. Survey research is useful in that it is able to collect data from large numbers and it is possible to correlate respondent characteristics with the variable of interest, but such analyses often lack the depth and detail required to effect or guide significant service change. For example, in El-Turabi et al's (2013) analysis, it was unlikely that decision-making regarding treatment options was limited to a single point of contact between patient and healthcare professionals. However, the use of forced response or closed questions would cause the respondents to either collate

their experiences into an overall satisfaction rating or the 'rating' would be based on the most recent and/or memorable experience. This does not provide any detail about what it is like to be a patient involved in making decisions or the facilitating or inhibiting factors that influence the process.

The terms *patient experience* and *patient satisfaction* are frequently used interchangeably in the literature. This is inappropriate as the two terms address different perspectives of health care delivery. Patient satisfaction differs from patient experience in that it does not consider the actual events in detail; the emphasis is on whether expectations have been met and the degree (usually expressed numerically) to which they have been met. Satisfaction is a complicated, multidimensional concept based on the relationship between experience and expectation that has not yet been fully defined (Hawthorne 2006, Heidegger, Saal and Neubling 2006). Coulter, Fitzpatrick and Cornwell (2009) suggested that patient satisfaction ratings reflect four factors:

- The personal preferences of the patient
- The patients' expectations (these can be influenced by numerous factors e.g. own, friends and family experience, the media, the NHS, culture)
- Response tendencies due to personal characteristics
- The quality of care received

The measurement of satisfaction is dependent on the assumptions made by the researcher about what satisfaction means and this is often defined by the healthcare organisation's agenda rather than by the service users (Coulter, Fitzpatrick and Cornwell 2009). However, as Gill and White (2009) highlight "the continued misuse and perpetuation of the inter-changeability of terminology not only compromises the

worth of research, it inhibits the possibility of addressing how best to conceive and measure health service quality from the patients perspective" (p15).

The extent to which survey research of patient experiences and satisfaction can inform the delivery of high quality care is questionable. The NHS inpatient survey (Care Quality Commission 2015) is an example of where repeatedly positive overall experiences of hospital admissions are reported. However, these findings are not reflected in the general public's negative perception of the NHS and the quality of the service they expect to receive (Edwards 2006, Healthcare Commission 2006). Naithani et al. (2008) conducted a study that is a good example of how the quality of information that can be obtained differs depending on the research approach used. The authors discuss how national survey data of patient satisfaction with food received in hospital had changed very little over a number of years (Care Quality Commission 2015). However, in the same time period, issues of malnutrition of the elderly in long term care facilities and failure to adequately address acute care patients' nutritional needs have been reported (Age UK 2010). Naithani et al. (2008) therefore aimed to explore patients' experience of hospital food using a qualitative approach and observation and post discharge semi-structured interviews as the methods of data collection. Their results suggested that although most patients were happy with the quality of food received almost half had experienced feeling hungry and had encountered a variety of difficulties in accessing suitable food. The study presented new information about the factors that impacted patients' experience of mealtimes including organisational barriers and a key theme emerged that patients frequently felt hungry. The experiences of patients who were too unwell (either physically or due to cognitive deficit) were not captured. This study highlighted that patients' can be satisfied overall with an experience but by using a qualitative

approach further in-depth issues can be identified which can inform the organisation's service improvement decisions. Further information on sampling strategy and methods to enhance rigour e.g. reflexivity would have further enhanced this study.

Ziebland, Evans and Toynbee (2011) highlighted the complexities surrounding patient experiences through a qualitative study that used in-depth semi-structured interviews to explore individual experiences of lymphoma care. The emergent concept these authors described was that patients were "surprised" at having received positive experiences of lymphoma care in the NHS. It became apparent to the authors that there was disparity between the public expectations of NHS care and the actual experiences of care reported by individuals. The additional consideration of how the participants framed their experiences made this study particularly interesting – their positive experiences were conceptualised as being due to their own "good fortune" rather than reflecting the high quality service expected from the NHS. The authors concluded that: "People may be able to maintain the apparently contradictory opinions that the NHS is not very good, although their own experience of care is excellent, if they construct their own experience as 'lucky'" (Ziebland, Evans and Toynbee 2011: p26). The authors provide a clear description of the methods used for sampling, data collection and analysis, including some strategies of rigour (peer review of data analysis) promoting trustworthiness in the study design. The study could have been enhanced further by adopting a specific methodology and by providing more detail regarding researcher reflexivity. However, this is a very interesting study as it adds a new dimension to how people perceive and experience healthcare services. It highlights the complexities of patient

experiences that are difficult to capture using conventional survey research approaches.

2.4 Patient experiences of parenteral nutrition

No published research reports were found regarding the patient experience of parenteral nutrition (PN) specifically in acute care. This lack of research may be due to several factors:

- Patients requiring PN in hospital are often very unwell and some patients may not even be aware that they have received it
- In hospital mortality is greater for patients who require PN even once PN has been discontinued
- The patient population size is relatively small
- Research relating to PN in acute care is focused on other aspects e.g. reduction of complication rates or on the practice of nutrition support teams (NSTs)

Patient stories are accessible on the internet through patient support group forums such as, in the UK, Patients on Intravenous and Nasogastric Nutrition (PINNT 2015) and in the USA, the Oley Foundation (Oley Foundation 2015). Membership in these forums is highly valued by patients (Chopy et al. 2014). However, patient stories are difficult to utilise for service improvement as they often lack contextual information and it is not possible to explore in detail, interesting aspects raised by individuals.

In the absence of studies focusing on the acute care setting the available literature on the patient experiences of PN in the home environment was reviewed. Patients who require PN at home are still exposed to the risk of PN-associated complications, have to accommodate the routine of being connected to the PN bag,

may experience gastrointestinal symptoms, and may have altered ability to consume food and fluid. Research conducted in this environment may, therefore, highlight experiences that are similar to patients in the hospital environment. The main difference between the two environments is that patients at home will have a stable medical condition that has allowed them to be discharged from hospital and, as a result, they will have less interaction with healthcare professionals.

Fifteen research articles reporting thirteen studies investigating the patient experience of home parenteral nutrition (HPN) were identified (Chambers, Hennessey and Powell-Tuck 2006, Dreesen et al. 2014a, Dreesen et al. 2014b, Elphick et al. 2009, Huisman-de Waal et al. 2006, Huisman-de Waal et al. 2011a, Huisman-de Waal et al. 2011b, Huisman-de Waal et al. 2011c, Orrevall, Tishelman and Permert 2005, Oz, Theilla and Singer 2008, Persoon et al. 2005, Schliefert and Carey 2014, Tsang and Carey 2015, Winkler et al. 2010a, Winkler et al. 2010b) and an unpublished research report (Baxter 2015). The aims of these studies varied, some researchers focused on the overall patient experience (Orrevall, Tishelman and Permert 2005, Winkler et al. 2010a), whereas others explored specific aspects of the experience of PN, such as Winkler et al. (2010b) who focused on the changed meaning of food and eating in HPN patients and its impact on quality of life. Other researchers explored the impact of PN related problems experienced by patients on quality of life, for example the incidence or predictors of minor complications e.g. fatigue, muscle cramps in HPN patients (Elphick et al. 2009, Huisman-de Waal et al. 2006, Huisman-de Waal et al. 2011a), and how the incidence of PN complications are linked to psychosocial complaints (Huisman-de Waal et al. 2011b, Persoon et al. 2005).

Quality of life[6] (QOL) is commonly referred to in the HPN literature when considering patient experiences (Baxter, Fayers and McKinlay 2005). It is difficult to define QOL in this context but is generally considered to reflect the patients' perspective of their health status which, in turn, is shaped by their experiences (Baxter, Fayers and McKinlay 2006). It is explored using both survey and qualitative research approaches and discussed in the next two sections.

2.4.1 QOL in HPN patients using a survey research approach

A group of studies conducted in the Netherlands (Huisman-de Waal et al. 2011a, Huisman-de Waal et al. 2011b, Huisman-de Waal et al. 2011c, Persoon et al. 2005) adopted survey research approaches to investigate symptoms, problems and quality of life in HPN dependent adults. The methods utilised included postal questionnaires (Huisman-de Waal et al. 2011a, Huisman-de Waal et al. 2011b) and structured interviews (Persoon et al. 2005, Huisman-de Waal et al. 2006). The main findings from these studies were that poorer QOL correlated with fatigue, sleeping disorders, anxiety, depression and social impairment (Huisman-de Waal et al. 2006, Huisman-de Waal et al. 2011b) and with seven categories of problems described by Huisman-de Waal et al. (2006) as negative emotions, physical problems, social limitation, dependence on others, incapability, complications and patient care provider related. Furthermore, those patients who had experienced HPN related complications e.g. central venous catheter related bloodstream infection (CRBSI) or occlusion had a higher occurrence of psychosocial complaints (Huisman-de Waal et al. 2011b). Interestingly, patients, despite being satisfied overall with healthcare professionals, identified that a lack of attention was paid to the occurrence and

[6] The terms quality of life (QOL) and health-related quality of life (HRQOL) are frequently used interchangeably in the literature. QOL is a broad concept covering all aspects of life whereas HRQOL focuses on the effect of illness and the impact of treatment on QOL (Lin, Lin and Fan 2013). The term QOL has been adopted throughout this literature review as it is the most commonly used term within the HPN literature.

management of psychosocial problems at review appointments (Huisman-de Waal et al. 2011c). The limitations of these studies are summarised in Appendix 3 and relate to the lack of information provided about how the questionnaires were developed or validated and the focus of the questions on *problems* rather than the *overall experience*.

Elphick et al. (2009) also used a survey approach and conducted structured interviews with forty-five patients to ascertain the occurrence of minor complications associated with HPN at four centres in the UK. Demographic data was collected using a standard set of closed questions followed by a single open question *"do you get any side effects in relation to your HPN?"* with frequency and type of side effect recorded. This was then followed by the closed question *"do you have significant problems with muscle cramps?"* They concluded that muscle cramps were the most commonly reported side effect relating to PN infusion, occurring in 27% of patients. This was a very poorly designed study, it lacked description of methodological approach and sparse details were provided regarding the methods used. Focusing a question specifically on the occurrence of muscle cramps without also investigating other symptoms that can occur when receiving HPN is a major limitation of this study. The results cannot be interpreted as conclusive due to the poor study design.

Chambers, Hennessy and Powell-Tuck (2006) took a different approach from the previous studies by investigating quality of life as an outcome measure in a randomised controlled trial (RCT). Their longitudinal study involved thirty patients from eight UK HPN centres who were randomised to either receive telemedicine (video-calling) for follow up contact or standard telephone contact. Patient QOL was assessed at the time of discharge home on HPN and during the subsequent post-discharge year using standardised validated and reliable tools - the SF36

questionnaire (Ware and Sherbourne 1992), EuroQol (EQ5D) (EuroQol Group 1990), and the Hospital Anxiety and Depression Scale (HADS) (Zigmond and Snaith 1983). QOL scores were noted to be significantly lower than normative data at the point of discharge but they significantly improved over the first six months in both groups in physical functioning, physical role, vitality, social functioning, emotional-role domains and mental component summary. The use of telemedicine had no impact on QOL scores. Opiate use was correlated with reduced scores on numerous SF36 questionnaire domains and also with the number of inpatient admissions for CVC reinsertion. At one year the attrition of each group meant that further statistical analysis was not possible. The reasons stated for this attrition were death (n=8), bowel adaptation negating the continued use of HPN (n=7) and loss to follow up (n=1). Attrition can greatly affect the strength of findings in a randomised controlled trial through loss of homogeneity in the two study groups. However, in this study, participants were randomised to receive either telemedicine or standard telephone contact, but no attempt was made to evenly distribute participants between the two groups depending on other characteristics e.g. age, sex, diagnosis, which is a further limitation of the study. Attrition can introduce bias if the characteristics of participants lost to follow up differ between the randomised groups (Dumville, Torgerson and Hewitt 2006). Strategies used to reduce loss to follow up such as incentives and reminders (Brueton et al. 2014) would not have enhanced this study as the attrition was predominantly due to death or the participant no longer requiring HPN which can be difficult to predict. A larger sample size with homogeneous groups would have strengthened this study and enabled the aim of assessing QOL at one-year post discharge to be achieved.

Earlier studies (Richards and Irving 1997, Price and Levine 1979, Jeppesen, Langholz and Mortensen 1999) suggested that people requiring HPN have a poorer QOL. However, there is some indication that QOL can improve over time. The difficulty of measuring QOL in this patient group is multifactorial and includes:

- The diversity or lack of heterogeneity of tools used to 'measure' quality of life and no validated tool had been developed for use with this patient group.
- A number of different aetiologies are associated with intestinal failure and the need for HPN: for example, patients who have a malignant disease requiring HPN as part of their palliative care management compared to those with benign disease.

Baxter, Fayers and McKinlay recognised this as a problem (Baxter, Fayers and McKinlay 2005, Baxter, Fayers and McKinlay 2006) and, in an effort to resolve it, developed and validated the first treatment specific questionnaire designed to measure quality of life in HPN patients (Baxter, Fayers and McKinlay 2008, Baxter, Fayers and McKinlay 2009). In the first international cross sectional study of QOL in HPN patients using this validated tool (Baxter 2015, unpublished) 699 patients from 14 countries completed the HPN-QOL questionnaire, (Baxter, Fayers and McKinlay 2008) with the majority of patients reporting a moderate/good QOL. Functional status improved and symptoms were reduced in those who had been on HPN for longer durations. There was some variation in QOL related to the underlying illness and also associated with different countries but overall this study indicated better QOL than suggested in previous studies and has the advantage of using a validated, disease specific tool.

Oz, Theilla and Singer (2008) also investigated QOL of patients with HPN in Israel using a survey research design. They also aimed to assess eating behaviours

of patients receiving HPN. Structured telephone interviews were carried out with fifty patients or their caregivers, using the Functional Assessment of Anorexia/Cachexia Therapy questionnaire (FAACT) (Ribaudo et al. 2000). They found that low physical activity level was associated with impaired quality of life and emotional status, and that oral intake was 'strongly altered'. They reported that this was independent of duration on HPN or patient age. The authors concluded that patients need to be encouraged to increase their physical activity levels, however no attempt was made to explore the impact that better clinical status might have on physical activity levels. Although interesting, this study had a number of issues, namely that the sample included both adults and children with 28% being aged 0 – 5. This limits the use of their data collection tool (FAACT) which has numerous questions specifically relating to work and sex life and may in part explain the poor response rates to questions: only three of twenty five questions were addressed by all fifty respondents. The questionnaire used was not treatment specific and it was not validated for use in this group. In addition, the article itself had numerous typing errors and referencing anomalies affecting its credibility.

In an Australian study (Schliefert and Carey 2014) the nutritional status and QOL of eight HPN patients was investigated using a survey approach. Nutritional status was assessed using anthropometric measurements and subjective global assessment[7] (SGA), QOL measures were assessed utilising a self-administered SF36 questionnaire (Ware and Sherbourne 1992) and the HPN-QOL questionnaire (Baxter, Fayers and McKinlay 2009). The authors found that QOL scores using the SF36 questionnaire were below Australian norms based on age and gender with the largest difference being seen in role limitations due to physical health. Females

[7] Validated nutritional assessment tool

(n=4) were shown to have a poorer QOL according to the HPN-QOL questionnaire but this may reflect differing aetiologies causing intestinal failure. The authors highlight that the results from the two QOL questionnaires were not significantly correlated. However QOL is a difficult to measure multidimensional concept, particularly due to the lack of a single agreed QOL definition. This has led to a vast array of validated tools, both generic and disease-specific that have differing areas of focus. This study was limited by the small sample size (n=8) but was the first study of its type in Australia using validated QOL tools. Researchers now have a choice, when exploring QOL in patients who receive parenteral nutrition, whether to use a generic QOL measurement tool e.g. SF36, or to utilise a disease specific tool (HPN-QOL). Generic tools can be used to compare between different types of diseases and treatments or to normative populations, whereas disease specific tools may provide more detailed clinical information on the responsiveness to a treatment (Lin, Lin and Fan 2013). Using both approaches concurrently, as Schliefert and Carey (2014) have done, enables both disease specific information and comparison with normative values. However, it should not be anticipated that scores would be comparable using different methods as the measurement tools are focused on capturing different dimensions of QOL. It is also not surprising that QOL in HPN dependent patients was found to be lower when compared to normative values in the Australian population; this is due to the impact of chronic disease. Comparison with other chronic disease groups that are technology dependent could be more relevant, for example, haemodialysis patients. It is questionable whether it is possible to measure the QOL of a unique individual as many measurement tools fail to adequately capture the subjective experience of disease and treatment providing an

indication of health status[8] rather than QOL (Hamming and De Vries 2007). Hamming and De Vries (2007) assert that there are no 'standard' or 'normal' values of QOL and measures can only be usefully compared with a patient's previous scores rather than those of other patients. In clinical practice this would allow the clinician to focus and address areas that are negatively influencing the patients overall QOL. A further difficulty in patients with intestinal failure requiring PN is that the underlying disease may fluctuate over time, which may not reflect the impact of the treatment (HPN) itself but the nature of the underlying condition (Velanovich 2009).

The studies discussed generated information about QOL, frequency of problems, and the degree to which these problems affect patients. They do not explore patient experience as defined earlier in chapter one (Cornwell 2010, Department of Health 2005, Goodrich and Cornwell 2008). QOL measures are difficult to interpret when different data collection instruments are used and due to the diversity of the underlying aetiology that has necessitated the use of HPN. This may improve in future research with the development of the HPN-QOL validated tool providing the opportunity for some standardisation to measurement of QOL in this patient group. The interpretability of the findings in the studies is further limited by research frequently focusing on specific problems without consideration of the potential concurrent positive aspects of receiving PN.

2.4.2 QOL in HPN patients using a qualitative research approach

Tsang and Carey (2015) conducted a qualitative study the purpose of which was to explore the impact of HPN on daily living in a cohort of Australian patients. Eight participants receiving care from a tertiary hospital were recruited to take part in either

[8] Health status refers to physical, mental and social functioning but bears no relationship to the perception of the individual and their values/expectations (DeVries and Drent 2006)

face to face or telephone semi-structured interviews. The authors found that, despite the limitations caused by HPN in taking part in social events and travelling, HPN had improved their QOL overall and was considered to be life saving. The majority of participants were able to eat, and enjoyed food, albeit taking smaller portions to reduce the occurrence of gastrointestinal symptoms. The authors concluded that earlier commencement of HPN may be warranted in order to improve the QOL for patients with chronic gastrointestinal disorders. Interestingly, in this particular study the participants did not feel that HPN had a significant impact on their social activities which is in contrast to the previously described studies in the Netherlands (Huisman-de Waal et al. 2006 and Persoon et al. 2005) which found significant social impairment. This difference may reflect the aims of these studies which was to identify *problems* related to receiving PN rather than consider the overall experience.

Dreesen et al. (2014a) conducted a qualitative study using in-depth face-to-face semi-structured interviews with twelve HPN patients in Belgium in order to identify what patients considered to be the most important outcomes associated with having HPN. Nine main outcome categories were identified: gaining weight, improving QOL, optimal survival, number of catheter related bloodstream infections, number of catheter obstructions, readmission to hospital, improving sense of energy, living without fear/anxiety and regaining freedom or independence. These outcomes were used to develop a multicentre survey (Dreesen et al. 2014b). Respondents were asked to rate each outcome listed using a Likert scale to indicate the importance in their care, to rank the three outcomes most important to them, and to suggest other outcomes not included in the survey. The aim was to identify the three most important outcomes related to HPN care in order to help healthcare professionals to focus on patient priorities. Overall, reduction of incidence of catheter related

bloodstream infection, survival and quality of life were considered the most important, but the authors noted that there were significant differences between the HPN centres. An expert panel in an earlier study (Dreesen et al. 2012) found similar results, however, the differences between the reporting centres may indicate that the complexities of HPN care are difficult to reduce to three key outcomes. In addition, the initial outcomes identified by Dreesen et al. (2014a) involved a cohort of HPN patients with both benign and malignant underlying disease and limited to those who had been on HPN for <180days. In contrast, in the multicentre survey (Dreesen et al. 2014b) recruitment focused on those with benign disease only and the HPN treatment duration was not restricted thus the desired outcomes identified by patients may differ.

Winkler et al. (2010a) used a qualitative approach to obtain a deeper understanding of living with HPN and content and an interpretative phenomenological approach to analyse the data. In-depth telephone interviews were conducted with twenty-four adult participants who were encouraged to "tell their stories". A template of open questions with further probing questions as needed was used. Orrevall, Tishelman and Permert (2005) also used a qualitative approach and face-to-face semi-structured interviews as their method of data collection to explore the experience of HPN from the perspective of advanced cancer patients and their family members. In both these studies (Orrevall, Tishelman and Permert 2005, Winkler et al. 2010a) the patient experience was considered holistically and a higher level of "good" QOL was reported than in previous studies (Huisman-de Waal et al. 2006, Jeppesen, Langholz and Mortensen 1999). The benefits attributed to HPN included having more energy, gaining weight and improved strength and stamina and these improved the ability to carry out everyday tasks and attend social events.

The factors influencing QOL, reported by participants, were their overall health status, “being able to eat what I want, when I want”, abdominal pain, stamina, diarrhoea, presence of an ostomy and degree of flexibility in HPN infusion schedule (Orrevall, Tishelman and Permert 2005, Winkler et al. 2010a). Participants viewed HPN as a “lifeline” and a “nutritional safety net” and experienced a sense of relief and security that their nutritional needs were being met and perceived HPN to be a life sustaining therapy (Winkler et al. 2010a). The experience of being attached to the technology of HPN was discussed in terms of being “hooked up” and “tied down” and imposing restrictions on their family life, however, the participants felt that the benefits provided by the therapy outweighed the negative aspects (Orrevall, Tishelman and Permert 2005, Winkler et al. 2010a). The participants perceived their lives to be normal; however, they had redefined what ‘normal’ was in the face of their circumstances (Winkler et al. 2010a). By considering the whole patient experience using a qualitative approach, these studies were able to demonstrate both positive and negative aspects related to the treatment and were able to explore how the participants’ experienced HPN. These studies provided more depth and understanding of what it is like to receive PN at home.

2.4.3 Food and eating in HPN dependent adults

Winkler et al. (2010b) focused on an analysis of the data obtained from their original study specifically related to food and eating (Winkler et al. 2010b). Out of the twenty-four participants, the majority (n=23) with short bowel syndrome[9] were able to eat; one person with pseudo-obstruction[10] ate infrequently due to dysmotility and

[9] Short bowel syndrome is caused primarily by extensive bowel resection leaving the individual with inadequate bowel length to absorb nutrients, fluids and electrolytes adequately.

[10] Pseudo-obstruction is a disorder of intestinal motility where peristalsis is inefficient resulting in an inability to propel food and fluid through gastrointestinal tract. Symptoms consistent with a mechanical bowel obstruction occur e.g. abdominal distension, nausea and vomiting, abdominal pain, constipation, however upon investigation no blockage will be found

pain. Those participants less affected by diarrhoea and gastrointestinal pain ate more than those who were symptomatic. Eating was perceived to be a “waste of money” by many, due to the inability to gain sustenance from the food. HPN provided relief and security in the knowledge that nutritional needs were being met. Eating prior to HPN was described as a “chore” due to its link with gastrointestinal symptoms. The authors (Winkler et al. 2010b) described three patterns of eating that emerged from the data analysis:

- Eating for survival: A period prior to HPN described as a vicious cycle of continuing to try and eat sufficient amounts followed by severe gastrointestinal symptoms resulting in malnutrition, depression, anxiety and poor QOL
- Eating for health benefits: Following dietary plans to promote intestinal adaptation to reduce the reliance on HPN
- Eating for socialisation: HPN as a safety net reduced the pressure to eat so that some enjoyment could be had from eating once more. Being able to eat small amounts during social occasions was associated with better QOL

The ability to eat food was an important aspect of the lives of HPN dependent adults with intestinal failure and had a significant impact on self reported levels of QOL through provision of nutrients, promotion of health and providing a sense of community and belonging. This study adds new knowledge to the meaning of food and eating in HPN patients. The study design is good and well described, however, the inclusion of details about the researchers and their involvement in implementing the study would have enhanced the rigour of the study.

2.5 Conclusion

In this literature review survey research was neither able to provide adequate detail regarding patient experience nor capture the variations in care and treatment experienced. Qualitative research was found to provide depth and detail, capturing both positive and negative aspects of experiences, and enabling these experiences to be contextualised. This assists the reader to understand the impact that this therapy has on the daily lives of patients. Despite the literature related to HPN being interesting and relevant to those working within the field of PN, these studies were unable to inform an understanding of the experiences of those requiring PN within the acute care setting. The decision was therefore made to undertake a qualitative study exploring the patient experiences of PN in the acute healthcare setting. This is an important area of practice to explore because i) this aspect of care was not addressed during a review of nutritional services at the research site and subsequently identified as a limitation of the review, and ii) no previous research has explored patient experiences of PN in acute care.

Chapter 3: Methodology

3.1 Research aim and objectives

The aim of this study is to explore the patient experiences of receiving parenteral nutrition (PN) in an acute teaching hospital. The specific objectives are:

- To describe the events leading to patients requiring PN
- To describe the experience of receiving PN
- To explore the experience of care received

3.2 Methodology Introduction

The aim of this study is exploratory, it seeks depth and understanding of the topic in question therefore the qualitative paradigm was chosen as an overarching approach to the research. Qualitative research "involves an interpretive, naturalistic approach to the world" meaning that researchers try to "make sense of, or interpret phenomena in terms of the meanings people bring to them" (Denzin and Lincoln 2011: p3). It is a "human science rather than a natural science. It explores the textured meanings and subjective interpretations of a fluid, uncertain world" (Finlay 2011: p9). Qualitative research provides opportunity for depth and breadth of participant response which allows positive, negative and paradoxical views and experiences to be captured (Bate and Robert 2007, Liamputtong 2010, Ziebland, Evans and Toynbee 2011). Qualitative research utilises less structured methods of data collection; this allows participants to express themselves freely, to tell their unique story and enables interesting or unexpected topics to be explored. These characteristics enable rich and insightful descriptions to be formed in order to provide new understandings, in this case regarding parenteral nutrition in acute care.

3.2.1 Why adopt a methodology in qualitative research?

Generic approaches can be taken to qualitative research and have been advocated by some (e.g. Smith, Bekker and Cheater 2011) in order to provide pragmatic ways to carry out research when the research purpose is relatively straightforward and uncomplicated and there is little time to become knowledgeable about the various qualitative methodologies and the underpinning philosophical approaches. However, Giacomini (2010) asserts that: “without an orientation to theory and its myriad forms in health and social fields, researchers risk incoherence” (p146). She goes on to suggest that: “the adoption of a specific research methodology allows researchers to chart their course in and through their research projects” (p146). According to Denzin and Lincoln (2011) the researcher “approaches the world with a set of ideas, a framework (theory, ontology) that specifies a set of questions (epistemology) that he/she examines in specific ways (methodology, analysis)” (p11). Researchers choosing not to adopt a specific methodological approach may risk a resultant study design that is not congruent with their own ontological and epistemological concerns.

Methodological theories give researchers different *lenses* through which to look at complicated problems and social issues, focusing their attention on different aspects of the data and providing a framework within which to conduct their data collection and analysis (Reeves et al. 2008). The “quality of a qualitative research study will be influenced by how the researcher attends to theoretical concerns at different stages of the research” (Kelly 2010: p285). Adopting a methodology enables the researcher to describe the processes and decisions made in the study design and also to present the findings in the discussion while ensuring that there is coherence of all the components of the study design.

The methodology chosen for this study was phenomenology which was congruent with the researcher's relativist ontological position – that there are multiple realities and subjectivist epistemology – that the participant and researcher work together to uncover the meaning of the phenomenon in question (Denzin and Lincoln 2011: p13).

3.3 Philosophical phenomenology

Philosophical phenomenology rose to prominence with the work of Edmund Husserl (1859 – 1938), who is credited as being the founder of modern phenomenology (McWilliam 2010). Husserl sought a new way to understand reality and he believed that subjective experiences could offer insight into different realities. He wished to move away from the positivist experimental approaches to science, believing that the study of consciousness could be rigorously studied in an objective manner (Moran 2000, Lewis and Staehler 2010, McWilliam 2010). The emergence of phenomenology in the 20th century was significant because it offered a method of accessing the difficult phenomena of human experience. Husserl defined the science of phenomenology as the study of the *essence* of conscious experience, his aim being the description and structural analysis of consciousness as it is given (Finlay 2011). Husserl "exhorted phenomenologist's to go all out to capture the richness and ambiguity of the "thing"" (Finlay 2011: p3). Husserl's writings on phenomenology developed and evolved over his lifetime, as such, some of his ideas have remained open without clear definition (Giorgi 2010). As a result, subsequent phenomenological philosophers have been diverse in their interpretation of phenomenological concepts (Lewis and Staehler 2010). This has led to uncertainty

over how to apply philosophical concepts to empirical research (Finlay 2009, Moran 2000).

Phenomenology is “a methodological approach with a strong and dynamic philosophical and epistemological foundation that seeks to understand, describe and interpret human behaviour and the meaning individuals make of their experiences” (Carpenter 2010: p125). Phenomenological research is concerned with returning to “embodied, experiential meanings aiming for a fresh, complex, rich description of the phenomenon as it is concretely lived” (Finlay 2009: p6). Phenomenology recognises that “human nature and experience is complex and multidimensional “(McWilliam 2010: p242). It does not categorise or explain behaviour nor does it generate theory (Finlay 2011), but “allows researchers to gain insights and inform practice strategies and enhance practitioners understanding of, and sensitivity to those they serve” (McWilliam 2010: p229).

In phenomenological research the aim is to encounter the phenomenon through the person’s description. The phenomenon is the object of investigation not the person; participants are encouraged to fully describe the phenomenon from their perspective, in this case, parenteral nutrition (Englander 2012). Finlay (2011) asserts that the challenge of phenomenology is to move away from the individual participant accounts and focus on the phenomenon, a further challenge is to break free of the literal meanings of what participants say is their experience and to intuit implicit meanings. The accounts of a person’s lived experience “get transformed through in-depth analysis, into textual description[s] of the essences of the phenomenon – a description which hopefully resonates and evokes the experience” (Finlay 2011: p16).

Although there are many variations in the way that phenomenological research is conceptualised and conducted, two broad categories are commonly described in the literature – interpretive (or hermeneutic) phenomenology and descriptive (or eidetic) phenomenology (Carpenter 2010, Lopez and Willis 2004, Rapport 2005, Todres 2005). Interpretive phenomenology developed from the work of Martin Heidegger (1889 – 1976), who was a student of Husserl's. Heidegger believed that description alone was inappropriate for making sense of human experience because humans are self-interpreting beings that already understand their situation in a pre reflective state (Heidegger 1962, cited in Finlay 2011). In interpretive phenomenology "lived experience is thematicised through language and understood by being refracted through a variety of lenses - philosophical, theoretical, literary and reflexive" (Finlay 2011). Heidegger extended hermeneutics, the philosophy of interpretation, and the phenomenological work of Husserl to study being in the world rather than knowing the world (Reiners 2012). Heidegger wanted to go beyond the descriptive phenomenology of Husserl and seek meanings that are embedded in everyday occurrences (Lopez and Willis 2004). Heidegger's approach to phenomenology does not require bracketing; this is because hermeneutical philosophy presumes prior understanding (Dahlberg, Drew and Nystrom 2001).

The other category, descriptive phenomenology is guided by the philosophical work of Husserl and has been developed extensively by Giorgi and others (Finlay 2011). It examines everyday conscious experiences derived from the participants' natural attitude while preconceived opinions are set aside or bracketed (Husserl 1931 / 1913). It is firmly rooted in the data that is shared by the participants during the research process and describes the essence of the experience without the influence of any external theory (Reiners 2012).

For Husserl the critical question was “what do we know?” whereas for Heidegger it was “what is being?” (Reiners 2012). According to Dahlberg, Drew and Nystrom (2001) Heidegger asserted that the essence of human understanding is hermeneutic, that is, our understanding of the everyday world is derived from our interpretation of it. Interpretive phenomenology is used when the research question asks for the *meaning* of the phenomenon and there is no wish to bracket prior experiences whereas descriptive phenomenology is used when the research seeks to describe the phenomenon and to bracket out presuppositions. This study utilised a descriptive phenomenological methodology.

3.4 Descriptive phenomenology

Descriptive phenomenology is grounded in the philosophy of Husserl (Finlay 2011). Amedeo Giorgi, an American psychologist, is credited with developing the philosophical phenomenology of Husserl into a rigorous phenomenological *method* for studying psychological research questions (Applebaum 2011). As stated by Giorgi (2010) “phenomenological philosophy is a foundation for scientific work; it is not the model for scientific practice. The insights of the philosophy have to be mediated so that scientific practices can be performed” (p4). Giorgi (2009) described the key characteristics of descriptive phenomenology as:

1) It is rigorously descriptive
2) It uses phenomenological reduction
3) It explores the intentional relationship between persons and situations
4) It discloses essences immanent in human experiences through imaginative variation

Husserl took the term *intentionality,* originally described by Brentano, and used it in a different way, referring to consciousness as being intentional, in the sense that it is directed towards something - consciousness is consciousness of something (Husserl 1913/1931, Giorgi 1997, Finlay 2011). According to Giorgi (2009) this is a requirement of phenomenology – in this instance the consciousness needs to be aware and directed towards the experience of parenteral nutrition; this is why patients who were unaware or unable to understand the treatment they were receiving were excluded from the study.

Unlike interpretive phenomenology, descriptive phenomenology does not attempt to interpret the meanings of experience by bringing external theory to bear (Finlay 2011). According to Giorgi (2009) "the descriptive researcher obviously sees the same ambiguities that an interpretive analyst would see but is not motivated to clarify them by bringing in non-given or speculative factors" (p127). Full description is prized above any kind of explanation or theorising - why a person might have said something matters less than what might be revealed in the saying / experiencing (Finlay 2011). In descriptive phenomenology "the researcher brackets past knowledge / presuppositions; the description is broken into meaning units; then psychological meanings are systematically extracted and imaginatively varied to obtain a rigorous account of the general structure of the phenomenon" (Finlay 2011: p88). Phenomenological description is committed to staying true to the experience and reveals the essential structures that are presented to consciousness thus elucidating what constitutes the essence of experience. The phenomenon in question is: "whatever is given, or present[s] itself, is understood precisely as it presents itself to the consciousness of the person entertaining the awareness" (Giorgi 1997: p238).

Husserl defined the science of phenomenology as the study of the *essence* of conscious experience (Husserl 1913 / 1931). Essence refers to "invariant structures that can be intuited within an experienced world of meaning" (Todres 2005: p105). They are "the general structure [that] is made up of constituent parts that relate to one another in a coherent way" (Todres 2005: p114). Once the essences or themes have been obtained from analysis of the data there is a requirement to intuit the essences to enable the discovery of the invariant features. This is done through the use of *imaginative (or eidetic) variation*. This is a method of "imaginatively varying the constituents of the experience in order to consider its boundaries and internal relationships" (Todres 2005: p105). It was first described by Husserl (1913/1931) and involves freely removing or changing aspects of the phenomenon in order to distinguish essential features from particular or incidental ones (Wertz 2010). The following concepts characterise descriptive phenomenological research:

3.4.1 The lifeworld

The focus of descriptive phenomenological research is on the "*Lebenswelt"* or *lifeworld*. It is "a meaningful structural whole that is both shared and experienced by individuals each from their own unique perspective" (Finlay 2011: p45). The lifeworld is the world as we encounter it in everyday experience (Giorgi 2009). Lifeworld experiences are provided by "other people who have lived through such experiences and who are able to describe such happenings in context, and as richly as possibly" (Todres 2005: p108). The lifeworld is "the world of pre-theoretical experience which is also that which allows us to interact with nature and to develop our own cultural forms" (Moran 2000: p181). The lifeworld both informs and contextualises the perceived meanings of the world.

Patients' experiences of illness or disease need to be understood as embodied experiences: they involve both the body and the lifeworld of the patient (Merleau-Ponty 1962, cited in Finlay 2011). When patients tell their stories they give voice to their lifeworlds (Giorgi 2009). The experience of receiving parenteral nutrition in hospital will influence the individual's lifeworld and be set within the context of all their previous experiences. The lifeworld encompasses a person's sense of lived time, space and embodied relationships with self and others (van Manen 1990). Finlay (2011) describes the four fundamental lifeworld themes proposed by van Manen (1990) as a guide for reflection on research:

1) Lived space (spatiality): the way space is experienced e.g. a safe environment versus a threatening environment
2) Lived body (corporeality), the way our body feels e.g. when we feel tired, in pain, energised
3) Lived time (temporality) subjective time experienced e.g. a short meeting can feel long in duration when the topic is perceived as uninteresting
4) Lived human relation (relationality), our experience of others e.g. when we get increased feelings of self worth when viewing your own parents pride in your achievement

These fundamental themes were used to guide data analysis and the discussion of the results in later sections of this dissertation. An individual experiences the lifeworld from the perspective of the natural attitude, that is, they are pre-theoretical without attempts to understand or make sense of the experience (Giorgi 2008). Phenomenological researchers must move away from this natural attitude when conducting a study to prevent the researcher's own lifeworld influencing the way they

experience the data. Instead the researcher adopts the *phenomenological attitude* (Giorgi 2010) through *phenomenological reduction*.

3.4.2 Phenomenological reduction

Phenomenological reduction (also referred to as epoché or bracketing) is a fundamental part of descriptive phenomenology. It involves adopting the "phenomenological attitude", a critically reflective state where nothing is taken for granted, as opposed to the "natural attitude" of the participants (Giorgi 2009). It is the method that allows the intentionality of consciousness to be explored – to understand the individual person's lifeworld experience. The reduction involves a personal transformation and "reorientation of the natural mundane attitude" (Husserl 1970/1936: p258 cited in Finlay 2011: p46). Husserl argued that we must work to free ourselves from prejudices and previous understandings and secure a level of detachment from our own history (Finlay 2011). This involves *bracketing:* the process of identifying and holding in abeyance preconceived beliefs and opinions about the phenomenon under study (Polit and Beck 2004). This includes what we know about scientific theory and knowledge and our own experiences (Finlay 2011). It is important to adopt this approach throughout the research process, to look at the data with relative openness without presuppositions influencing the analysis (Giorgi 1994). This allows the researcher to see and hear the participant as someone who "perceives, represents, thinks, feels, desires and so forth" (Husserl 1931 / 1913).

Phenomenological reduction invites researchers to "dwell repeatedly with and immerse themselves in the immanent experience of appearances in order to discover emergent patterns of inter-related essences revealed in actual experience" (Finlay 2011: p45). According to Applebaum (2011) "we are the emphatic witnesses of the others account of their experience, seeking to unfold its essential

intersubjective meanings" (p524). Descriptive phenomenology requires a change in attitude of the researcher. It involves stepping away from what we know and viewing the world through the eyes of the participants. Phenomenological description enables researchers to tap into the ambiguity and contradictions inherent in experience in order to capture layers of complexity (Finlay 2011: p18).

Phenomenological research in practice differs from the philosophical approach in that it is not focused on *pure* self-reflection but rather on other peoples' accounts (Finlay 2011). Through the process of phenomenological reduction, preconceived ideas can be suspended and the researcher's attention focused solely on the phenomenon in question, thus enabling the researcher to intuitively grasp the essence of the object (Moran 2000, Lewis and Staehler 2010). The goal is to present the essences of the phenomenon – in this case parenteral nutrition, from how it presents through the consciousness of the study participants rather than from what the researcher believes is known about the topic already.

Merleau-Ponty asserted that "the most important lesson that the reduction teaches us is the impossibility of a complete reduction" (Merleau-Ponty 1962: pxiv cited in Finlay 2011) and suggested that bracketing reveals the "prejudices" and taken for granted presuppositions not explicitly recognised in spontaneous, unreflective experience. Giorgi (2012), however, contends that being able to completely bracket out one's own thoughts and feelings was never Husserl's goal and that the key is to be mindful of one's presuppositions and how they may influence the research process. The idea of bracketing is "to connect directly and immediately with the world as we experience it – as opposed to thinking about it" (Finlay 2011: p23). The aim is not to create objectivity rather to promote

engagement with the narrative surrounding the phenomenon, to be interested and open to what appears (Giorgi 2010).

There is much debate and uncertainty about the concept of bracketing and its application in 'real world' research (Finlay 2011). It is considered to indicate rigour of the phenomenological method, however, how to do it is less well defined (LeVasseur 2003). Some critiques of the method mistakenly assume that bracketing should be applied to *all* phenomenological research – this is not the case. Bracketing is a feature of *descriptive* phenomenological studies and therefore readers with methodological understanding would not expect to see bracketing featured in an interpretive phenomenological study. The debate about whether the *complete* abeyance of one's own ideas is possible continues, however, Giorgi would contend that this was never Husserl's intent. Descriptive phenomenology does continue to be defined by a commitment to bracketing whereas interpretivists argue that the researcher's prejudgements can be used as data and enable meaning to be established (LeVasseur 2003).

Gearing (2004) suggested that there are three main foundational foci in bracketing:

1) It can refer purely to the process of setting aside, suspending or holding in abeyance presuppositions surrounding a specific phenomenon
2) It can refer to the process of focusing in on the essences and structure of the phenomenon, and
3) That bracketing most commonly combines aspects of both 1 & 2

He goes on to describe a typology of different types of bracketing that could be employed depending on which suppositions are required to be bracketed out. The use of bracketing in this study will be discussed in the methods section.

In conclusion, descriptive phenomenology was the methodological choice for this research as it recognises the value of human experience. Studies using "a descriptive phenomenological approach may 'humanise' health and social care, not just by representing the 'voices' and views of patients, users and professionals, but by accessing *descriptions* of experiences that carry intelligible meanings and textures of what it is like to be there" (Todres 2005: p117). The study objectives lend themselves to a descriptive approach because I am seeking to *describe* the experiences as they appear, it is an exploratory study, and there was no intent to provide theoretical interpretations, that is, to try and "make sense" of the data obtained.

A professional doctorate is rooted in researching practice-based issues and I considered it essential to ensure that the research was patient focused. By adopting a descriptive phenomenological approach the participants' stories, their voices, their experiences are heard. This has resulted in a description of the lived experience of parenteral nutrition in an acute hospital from the perspective of those who experienced it – the patients.

Chapter 4: Method

In this study the knowledge of the phenomenon in question (parenteral nutrition) was situated in the perspectives of the participants (Todres 2005). Therefore in order to obtain this knowledge the researcher needed to engage with the participants in a manner that would enable these experiences to be shared – this was achieved by using in-depth interviewing.

4.1 In-depth interviewing

In-depth interviewing is a method that dominates descriptive phenomenological research as it provides the opportunity for detailed descriptive data to be obtained from study participants by focusing on their conscious experience of the phenomenon. Other forms of data collection would either not obtain the depth of data (e.g. questionnaire) or would not have delved into the patient thoughts, feelings or emotions of the experience (e.g. observation) and thus would not be in keeping with the chosen methodology. The in-depth interviews conducted did not use fixed questions but instead engaged participants in conversation to elicit their understandings and interpretations (Carpenter 2010). This enabled the researcher to "explore the 'insider perspective', to capture, in the participants' own words, their thoughts, perceptions, feelings and experiences" (Taylor 2005: p39). Patient narratives are complex as they are multi-layered, reflecting the patient's own lifeworld. This includes their background and also their experience of the complex hospital environment in which they were cared for, and observed the care of others (Goodrich and Cornwell 2008, Finlay 2011).

Giorgi (2009) points out that "there are many books with advice on how to conduct an interview, but none happens to be written with explicitly phenomenological criteria in mind" (p122). He then goes on to say: "what one seeks

from a research interview in phenomenological research is as complete a description as possible of the experience that a participant has lived through" (p122). According to Todres (2005) a phenomenological interview "needs to be conducted in a way that clarifies rather than directs, while making sensitive decisions about keeping the interview focused on the phenomenon of the study. It is thus an open-ended interview that begins with the initial lifeworld-evoking question in all cases and then sensitively facilitates in-depth descriptions and narratives as they unfold "(Todres 2005: p111). Sorrell and Redmond (1995) also advocate the use of an open ended initial question as the most effective way of commencing a phenomenological interview as it gives the participants permission to tell their story.

Bevan (2014) attempts to provide more structure for those seeking to undertake phenomenological interviews by describing three aspects of the phenomenological interview method. The three structures are:

- **Contextualisation**: whereby the interviewer examines the experience in relation to the context and biography of the participant to give it meaning. This allows the narrative to be constructed and provides the opportunity for interesting areas to be explored. In this study this involved participants being asked broad descriptive questions about the events that led to them requiring parenteral nutrition, for example: *"tell me about the events that led to you needing parenteral nutrition?"*
- **Apprehending the phenomenon**, where the interview focuses directly on the experience of the phenomenon, exploring it and probing for further depth of information. Bevan (2014) suggests that descriptive questions are supplemented with structural questions to add depth and quality to the information attained, for example:

***Researcher**: So how did that make you feel in the middle of it all? [Descriptive]*

***'Sarah'**: [Sighs] certain lack of trust, erm, it, I....., just totally confused*

***Researcher**: So what did you end up doing, who did you listen to? [Structural]*

Transcript interview #10, page 5, lines 10-12

- **Clarifying the phenomenon**. To achieve clarification Bevan (2014) suggests the use of imaginative variation not purely within the data analysis phase of the process but also as a tool to actively examine the phenomenon during the interview. This enables imaginative variation to be "grounded in original context" (Bevan 2014: p142). This part of Bevan's process, although not actively adopted during this study, was still reflected in the interviews conducted, for example:

  ***Researcher**: Is there anything that could, could be done to try and help if you were in the same situation again, would anything have helped?*

  ***'Rebecca'**: I don't know, because, apart from having like a gourmet restaurant on site [both laugh]. You know, I, I don't know, I mean there, there were efforts made, to kind of change my diet and offer me things that might help, so, I don't know, I, I don't know, I think hospital food is what it is I guess isn't it? Erm, I don't know whether, 'cause my, my family brought food for me on occasion, erm, from the canteen and things which I ate, erm, and when I came home obviously, because I was allowed to come home at the weekends sometimes. I would try and eat as much as I could, erm, I still wasn't eating loads at home though to be honest, so, probably no, it probably wouldn't have made much difference*

  Transcript interview #4 page 9, lines 28-38

An assumption of phenomenological researchers is that it is possible to access the lifeworld of the individual through their description of their experience; this is however, dependent on the participant being able to provide a clearly articulated in-depth account (Edward and Welch 2011). All the interviews conducted involved some discussion of events and experiences unrelated to the research question. This was for two important reasons: i) experiences relating to parenteral nutrition are situated within the context of the lifeworld and it is therefore important to consider the

participant's story as a whole rather than through narrow, focused questions, ii) It is important to develop a rapport with the participants, for them to feel comfortable sharing not only the factual details of their experience, but also their thoughts and feelings.

4.2 Sampling

The study used a purposive sampling strategy, which involved the deliberate non-random selection of specific individuals because of the crucial information they could provide about parenteral nutrition (Bowling 2009, Carpenter and Suto 2008). All the participants had experienced intestinal failure, however, the aetiologies varied: an overview of the participant profile can be found in Appendix 4.

In qualitative research there is no set formula, equivalent to those used in quantitative research, to determine sample size (Morse 1998). Sampling within a phenomenological framework focuses on the quality of the sample rather than the size (Todres 2005) as some participants are less able to reflect and articulate their experience. When selecting participants for phenomenological research the question is not "how many people do I need" but "has this person had experience with the phenomenon in question"? (Englander 2012). The issues of how to determine the sample size and whether a defined sample size is needed are debated by qualitative researchers. Creswell (1998) suggested 5 – 25 interviews for a phenomenological study, whereas Morse (1994) recommended at least six. However these recommendations are wide ranging and lack empirical evidence to support their numerical value. In a review of sample sizes used in PhD research studies Mason (2010) highlighted that of the phenomenological studies reviewed, all had at least six participants as suggested by Morse (1994), while over two thirds

(68%) were within the suggested range of Creswell (1998). The remaining 32% had a sample size in excess of these recommendations. This suggests a desire on the part of research students to do more rather than less in order to have a defendable study (Mason 2010). Determining the best sample size for a study is challenging due to the multidimensional, complex nature of qualitative samples – they are dependent on the nature of the phenomenon being investigated, the number of times a participant is interviewed, the amount of knowledge and experience that the participant has to share and the duration of the interviews. However it remains a prerequisite of the ethical approval process. Therefore, from discussion with supervisors and considering the small patient cohort from which participants could be recruited the decision was made to aim for a sample size of 10-15. A range was stated in order to enable recruitment to continue until sufficient rich in-depth data was obtained (Liamputtong 2010).

Data saturation is reported to occur when little or no new data is being generated and new data fits into the categories already developed (Liamputtong 2010). Data saturation is a controversial concept in qualitative research as it is frequently poorly described in published research articles (Bowen 2008, Guest, Bunce and Johnson 2006). It can be argued that the point of saturation is never truly reached as new data is continually emerging as new participants are recruited; however, one also has to be pragmatic when conducting a research study. Saturation “involves eliciting all forms or types of occurrences, valuing variation over quantity” (Morse 1995); when no new concepts or patterns of understanding are evident in the data it will indicate that saturation has been reached. According to Morse (2000) there are several key things to consider when defending how data saturation was achieved:

1) The scope of the study – the broader the topic of interest the longer it will take to achieve saturation. Parenteral nutrition is part of a patient's overall journey of ill health. Focusing on the PN related aspects of the journey prevented the scope of this study from becoming too broad.

2) Study design – the phenomenological approach involved interviewing the participants at a single point in time to capture their story, their lived experience of receiving PN. As the intent was to hear their story recounted at a single point in time it was not necessary to do a series of interviews, neither would it have been likely to result in significantly more data.

The main factor affecting achievement of data saturation in this study was the quality of data provided by the individual participants. Some participants had poor recollections, were unable to articulate the events clearly and found it difficult to explore aspects in depth. After completing ten interviews there were no specific new topics relating *specifically to the experience of parenteral nutrition*, however, there were variations in the events that led up to requiring PN. Recruitment of participants was challenging, and the data collection period was prolonged. This was mainly due to the small cohort of patients from which participants could be recruited. The time constraints in place for the professional doctorate programme meant that a practical end point was required and it was therefore not possible to continue data collection further than 10 interviews. However, the sample size has been sufficient to provide significant new information about patients receiving PN in acute care.

4.3 Recruitment

The recruitment procedure is outlined in Appendix 5. Potential participants were identified from a parenteral nutrition database accessed as part of my clinical role.

Participants who received PN were assessed against the inclusion and exclusion criteria established for the study (see Table 4), patients who received it most recently were approached first. An invitation (Appendix 6) and participant information sheet (Appendix 7) explaining the purpose of the study and inviting potential participants to contact the hospital nutrition nurse specialist if they were interested, were sent by post. Due to my clinical role, some participants were known to me and this had potential to undermine the voluntary nature of recruitment. In order to avoid unintentional coercion the nutrition nurse specialist was chosen as the first point of contact. Participants contacted the nutrition nurse specialist and the study was explained and their questions answered. If they wished to proceed, I then contacted them by telephone to answer any further questions, if applicable, and to arrange a suitable time and location for interview.

Table 4: Recruitment inclusion and exclusion criteria

Inclusion	**Exclusion**
Patients who had intestinal failure requiring parenteral nutrition	Patients who were unconscious / confused or unable to understand PN
Received PN for >7 days	Aged <18 years of age
	Patients not yet discharged from hospital

Phenomenology requires that consciousness be *intentiona*l, that it is directed towards something (in this study parenteral nutrition), which is why patients who were unconscious or had no understanding of receiving PN were excluded. The inclusion criterion of PN being required for more than 7 days was included because PN is not typically provided for patients anticipated to require it for less than 7 days due to the risks of treatment outweighing potential benefits (Stewart et al. 2010).

Recruitment for the study took place between May 2012 and June 2014. This time period was longer than anticipated at the commencement of the study. This was due to several reasons 1) the researcher was on maternity leave, 2) a small

patient cohort was available from which to recruit, and 3) a proportion of the patients did not meet the inclusion and exclusion criteria, mainly due to them not being aware of PN as treatment.

4.4 Pilot test

Although an experienced clinical interviewer, I recognised that in-depth interviewing for the purpose of research requires very different skills that are frequently overlooked by researchers (Britten 1995). It was therefore imperative to practice these skills and reflect on my own abilities as a qualitative interviewer. Prior to the pilot interview I attended a qualitative interviewing course in order to become familiar with the theory and practical elements of this method of data collection. As it was not possible to carry out a full pilot study due to the small patient cohort a pilot interview was conducted with an existing home parenteral nutrition (HPN) patient who had extensive experience of PN and hospital admission. The pilot test allowed use of the audio-recording equipment, and question phrasing and flow to be practiced and refined prior to the main data collection. The pilot interview was recorded and fully transcribed and discussed with the supervision team. The data collected in this pilot interview was not included in the data analysis because the participant had not recently required PN in acute care.

4.5 Data collection

Interviews were carried out between May 2012 and June 2014 in locations chosen by the participants – eight interviews were conducted in participants' homes, two in the hospital where I work (one in a private room, the other on a ward at the patient bedside). I conducted all the interviews. The interviews varied in length, taking

between 28 and 105 minutes (average 66 minutes), and all were audio-recorded. The audio-recording allowed me to focus on the process of the interview and maintain good non-verbal communication e.g. eye contact to facilitate the process (Serry and Liamputtong 2010).

The interviews commenced with an informal, ice breaker type question such as “tell me a little about yourself”, as this allowed the participant to get used to talking to me and to the presence of the recorder. In some of the interviews this naturally led to the participant telling their story of ill health and need for PN. Where this did not occur a question such as “tell me about the events that led to you needing PN” was asked. Probing questions were used as required to encourage the participants to retell the events leading up to requiring PN and what it was like to have it. They were encouraged to give examples of the care (both positive and negative) they received and to describe their thoughts and feelings about the treatment process. Broad, open, descriptive questions were used with further probing, structural questions asked, as required, to elicit more information about the individual experience (Bowling 2009, Bevan 2014). A topic guide (Appendix 8) was used as a general guide, but the specific questions varied in each interview.

Following each interview I recorded my reflections in an electronic field note diary e.g. setting of interview, how the participant responded to questions, how the rapport was established during the interview and my abilities as a qualitative interviewer (for example field notes see Appendix 9). This enabled a context to be established to aid the interpretation of the interview data during the data analysis phase (Patton 2002).

4.5.1 Limitations of data collection

Interview 5 was not fully recorded. This was due to my failure to realise that there was insufficient memory capacity available on the recording device. When I realised the mistake time was spent documenting everything that could be remembered about the interview content in addition to the usual reflective narrative that was completed after each interview. The interview transcript plus my reflections were posted to the participant with explanation of the error that had occurred. The participant was asked to verify the transcript and reflections and highlight any additional information that was missing. The participant feedback was that he did not feel anything had been missed.

The ward based interview location for interview 9 was challenging. It was conducted at the participant's bedside, at her request; a private room near the ward had been suggested but was declined by the participant. This significantly impacted on the data obtained as within ten minutes of commencing the interview we were interrupted and it had to be resumed an hour later. It was also a noisier, more distracting environment and as the participant was less able to articulate her experience the interview was shorter.

4.6 Ethical considerations

A participant information sheet (Appendix 7) was provided which stated the purpose of the research project, what was involved, how the data would be used and provided assurances regarding confidentiality and anonymity. The participants had the opportunity to ask questions to ensure that they were fully informed and all participants were asked to sign a consent form prior to commencing the interview

(Appendix 10). Participants were informed that they had the right to withdraw consent at any time.

Ethical approval was obtained from the Coventry University Research Ethics Committee (Appendix 11) and the National Research Ethics Service (NRES) Committee Yorkshire and the Humber – Leeds West (Appendix 12). The NHS Research and Development Department at the hospital where recruitment took place also approved the study (Appendix 13).

Reliving past experiences of ill health had the potential to raise unexpected feelings of distress for the participants. This occurred in the pilot interview and interview 1. In both cases I offered words of comfort and reassurance and offered to terminate the interview or to have a break so the participants had time to compose themselves. In both cases they declined and wished to continue. After these interviews further support was offered to both participants. However, they both felt that discussing the sources of their distress with me had been sufficient and that there was no need for additional support. In both these cases the interview was stopped for a few minutes as the priority was to ensure the comfort of the participant by offering reassuring words of support and commenting on their experience.

Ethical issues exist relating to the balance of power between health care professionals as researchers and study participants. These issues are particularly salient for researchers who recruit patients, with whom they had a prior therapeutic relationship, as participants in research (Draper and Swift 2010). I had not had prior clinical contact with five of the participants, however, five of the participants had been treated by me in my clinical role whilst they were in hospital. To limit the impact of issues related to my clinician role I used bracketing and reflexivity

throughout the study process, encouraged open dialogue and consistently reassured participants that confidentiality would be ensured.

Following each interview, the participants were thanked for their involvement in the study. A summary of the study findings will be sent to all participants when it is completed.

4.7 Reflexivity and bracketing

In qualitative research the relationship between participants, researchers and their wider social world is actively acknowledged (Finlay 2011). Researchers recognise their central role in a co-construction of data and are required to explore this dynamic reflexively (Finlay 2011). Reflexivity is an "essential strategy that enhances the quality of research by making explicit the deep-seated views and judgements that affect the research topic, including a full assessment of the influence of the researcher's background, assumptions, perceptions and interests on the research process" (Carpenter and Suto 2008: p125). Reflexivity enhances methodological rigour and is associated with all qualitative research whereas bracketing is a concept characteristic of phenomenological inquiry (Giorgi 2010, Holloway and Wheeler 2010, Todres 2005). Bracketing is the process by which the researcher attempts to suspend all judgements and prior ideas in order to enter the unique world of the individual whose experience is the focus of the research (Carpenter 2010). However, in practice there is overlap between the two concepts. This is because in order to adopt the phenomenological attitude of openness to the natural attitude of the participant, researchers must first understand their own views through reflexivity.

Two strategies were used to address reflexivity and phenomenological reduction (bracketing) in this study:

- The use of a bracketing interview with an experienced qualitative researcher
- The completion of a reflective diary throughout the course of the interviews and data analysis process

A typology of bracketing was described by Gearing (2004) (Appendix 14), which was used to define and guide the bracketing process used in this study. Reflexive bracketing was chosen as its "focus is to make transparent, overt and apparent the researcher's personal values, background, and cultural suppositions" (Gearing 2004: p1445) (Appendix 15). Through the process of identification of the researcher's own suppositions and ideas about the phenomenon the impact on the phenomenon under investigation can be reduced (Gearing 2004). Reflexive bracketing demands that the researcher develop a thoughtful, conscious self-awareness (Finlay 2011, Gearing 2004). It was important to do this prior to data collection in order to prevent my thoughts from unduly influencing my interviewing approach. I made the decision to ask an experienced qualitative researcher (CC) to assist me with the bracketing process by conducting a bracketing interview (Rolls and Relf 2006). This is a strategy whereby the researcher is assisted in the exploration of their own personal and professional experiences and assumptions during data collection and analysis (Carpenter 2010). This was carried out to: 1) encourage me to describe my own knowledge and suppositions to make them fully explicit, and 2) provide the opportunity to explore issues of which I am not fully aware – the unconscious issues that another person may help me identify though the process of interview. One bracketing interview was carried out prior to data collection - this was fully transcribed so that it could be easily referred to during data collection and analysis. I also completed a reflective field diary through the course of the research, this was discussed with the supervisory team and the impact of the researcher's role was

considered at all points during data collection, data analysis and the subsequent discussion in the thesis. The reflective diary also provided an insight into my own abilities as an interviewer which was useful in developing and refining my interviewing technique (Carpenter and Suto 2008, Holloway and Wheeler 2010). Reflections from the bracketing interview and also extracts from an interview that proved to be challenging are presented in Appendix 16. These processes enabled me to clarify my thoughts and feelings both prior to and during the research process.

Through reflexivity I was able to define the origin of my interest in the research topic. It originated from my experience as a core member of a multidisciplinary nutrition support team, caring for patients with intestinal failure requiring parenteral nutrition and I had come to recognise the unique journeys that people have prior to, during and after requiring PN. Following a service review at the hospital it became clear to me that patients' views had not been explored and I was keen to improve the quality of the service we offered them. To do this I needed to understand the service better and that this should be achieved through in depth engagement with the service users. During clinical interactions, patients told me about the difficulties they experienced in coping with their symptoms, the onset of ill health, their altered relationship with food, and dealing with having artificial nutrition. Their experiences and accounts were diverse and there was not sufficient time in my clinical role to explore these in depth. I therefore sought the opportunity to explore these experiences in more detail, to learn from the patients, and to understand how we can provide a better service to those people who require PN. By recognising where I had come from through reflexivity, I was then able to use bracketing to hold in abeyance my prior understanding of PN in order to adopt the phenomenological attitude of

openness and prevent undue researcher influence particularly during the data collection and analysis phases (Polit and Beck 2004).

4.8 Strategies used to enhance the quality of the study

Qualitative research does not aim to be generalisable; it is considered insightful and exploratory and has different strategies for assessing rigour to quantitative approach (Denzin and Lincoln 2011, Holloway and Wheeler 2010). The concepts validity and reliability are primarily associated with quantitative research and, as used in that context, are considered to be incompatible with the ontological and epistemological foundations of qualitative research (Carpenter and Suto 2008). Criteria have been developed to judge the trustworthiness of qualitative research as an indicator of methodological soundness and adequacy (Holloway and Wheeler 2010, Lincoln and Guba 1985): credibility, transferability, dependability and confirmability. *Credibility* scrutinises the matter of "fit" between what the participants say and the representation of these viewpoints by the researchers (Padgett 2008). *Dependability* refers to whether the findings of the study are consistent and accurate (Holloway and Wheeler 2010). *Transferability* refers to the degree to which qualitative findings inform and facilitate insights within contexts other than that in which the research was conducted (Carpenter and Suto 2008). *Confirmability* has been described as "the degree to which findings are determined by the respondents and conditions of the inquiry and not by the biases, motivations, interests or perspectives of the inquirer" (Lincoln and Guba 1985: p290). Strategies used to enhance methodological rigour in this study included:

1) Peer review of the data (credibility). This involved utilising the supervision team who have experience in qualitative research procedures to assist and advise at

different levels of the analytical process. Peer review provided opportunity for undue researcher influence to be detected and offer alternatives to the researcher's own working propositions (Holloway and Wheeler 2010).

2) Member checking (credibility). This is advocated as part of Colaizzi's data analysis process (Colaizzi 1978) where the results are taken back to the participants. Member checking can occur at different stages of the analysis, from reviewing the written transcripts to reviewing summaries of the data analysis (Polit and Beck 2004). Member checking was voluntary, participants were asked if they wished to be involved and the degree of involvement was negotiated with each individual. Seven of the participants took part in member checking. In all cases the typed transcripts were returned to the participant for review, it was not practicable for participants to have written accounts at different stages of the analysis due to the prolonged period over which data collection was carried out.
3) Audit trail (dependability), the research process has been fully documented in this chapter and will be in subsequent disseminations to ensure that confidence can be had in the process. Equally sufficient detail will be provided in publications to allow other nutrition professionals to determine the relevance of the results to their own patient populations (transferability).
4) Reflexivity and bracketing were strategies used to enable my own experiences to be acknowledged in order to create openness to the participants' accounts through adoption of the phenomenological attitude (confirmability).

Chapter 5: Data Analysis

5.1 Introduction

The phenomenological data analysis process orientates the researcher to an "exhaustive, reflective and detailed analysis of each individual experience" (Carpenter and Suto 2008: p128). It requires that the researcher enter "the attitude of phenomenological reduction in order to become as faithfully present to the intrinsic intelligibility of the meaning of the narratives" (Todres 2005: p111). There are numerous approaches to descriptive phenomenological data analysis (e.g. Colaizzi 1978, Giorgi 2009, Hycner 1985, Wertz 1983). Key characteristics of all these methods includes time spent immersed in the raw data (audio recordings, written transcripts), followed by a process of gradual reduction of the data into meaning units and themes until a fundamental structure is determined (Todres 2005). The raw data should be returned to continually in order that the analysis remain grounded in the experience of the participants.

Colaizzi's (1978) framework (Appendix 17) for phenomenological analysis was used to guide the data analysis in this study. This method was chosen due to it being underpinned by descriptive phenomenological theory and rooted in the intent to describe the essence of the experience. The seven-step process of Colaizzi (1978) suggests a linear progression of data analysis. However, the actual analysis that took place was intuitive and cyclical. As Colaizzi (1978) explains:

> "These research procedures of analysis.....employed should be viewed only as typical and are by no means definitive; furthermore, they usually develop with much overlapping among them.....both the listed procedures and their sequences should be viewed flexibly and freely by each researcher" (Colaizzi 1978: p58-59).

What follows is a detailed explanation of how Colaizzi's process was adapted and used to guide the analytic process.

5.2 Managing the data

Qualitative data is renowned for being difficult to manage due to the large amount of data collected, for example the transcripts of the ten participant interviews were in excess of 110,000 words. Qualitative data analysis packages are available e.g. NVivo10 (QSR International 2012) to assist in the management of large amounts of qualitative data. There are pros and cons to using such software packages, a summary of which can be viewed in Table 5. Training was received on how to use NVivo10 (QSR International 2012), with the initial intent being to utilise this package. However, I quickly found the software to be restrictive, and Microsoft Word documents were better suited to my working style. In addition to this, concept maps (hand written and in PowerPoint) were used to enable comprehensive visualisation of the emerging concepts and themes and how they interlinked.

Table 5: The use of data analysis software – pros and cons (McLafferty and Farley 2006, St John and Johnson 2000)

5.3 The data analysis process

The following section summarises the data analysis process undertaken and how components of Colaizzi's method (1978) were utilised.

"Read all of the subject's descriptions.....in order to acquire a feeling for them, a making sense out of them" **(Colaizzi 1978: p59)**

Audio recordings of each interview were transcribed verbatim, into a Microsoft Word document, in order to transfer the data into a form that was possible to analyse (Serry and Liamputtong 2010). As I transcribed all the interview recordings, an initial understanding of the data was achieved (Giorgi 2010). Notes were made on emerging concepts and reflections on the inherent meaning of the participants' accounts using the comments function in Microsoft Word (Todres 2005). These were expanded upon further in the researcher's reflective diary.

The process of transcription allowed me to relive the interviews and become immersed in the data (Todres 2005). All of the recordings and transcripts were approached with an openness to whatever meanings emerged using the process of bracketing (Giorgi 2009). Bracketing, as described in the methodology chapter, is the process of identifying and holding in abeyance preconceived beliefs and opinions about the phenomenon under study (Polit and Beck 2004). Once the recordings were transcribed these were then read and re-read and the interviews listened to numerous times to allow for intonations, emphasis etc to be understood and further comments were added to the respective transcripts. My thoughts and feelings whilst listening or reading the experiences were recorded in my reflective diary (Sanders 2003). I did not designate a specific number of times that I would listen to the recordings as I found the length of time required to understand the interview as a whole varied. It was necessary to read or listen to the entire description because the phenomenological perspective is a holistic one (Todres 2005). The intent of the data analysis process is to see the phenomenon through the eyes of the participants as they share their experience (Todres 2005).

***"Extracting significant statements"* (Colaizzi 1978: p59)**

Significant statements are extracts from the transcript, in the form of words, phrases, sentences or paragraphs that directly pertain to the investigated phenomenon i.e. the experience of parenteral nutrition in hospital (Todres 2005). These units of meaning were identified by a slower re-reading of the description of the phenomenon provided by the participants (Giorgi 1997). By the end of this analytic phase a series of significant statements had been constructed but were still expressed in the participant's own everyday language (Colaizzi 1978, Giorgi 1997, Todres 2005).

I reviewed each complete transcript in Microsoft Word and highlighted words, sentences or paragraphs which related to the events leading up to requiring PN, PN itself and issues surrounding the care of PN as related to the research aim and objectives (for example see Appendix 18). The highlighted statements were then copied and pasted into a separate Microsoft Word document retaining the transcript, page and line numbers (e.g. 4.2.26-29) so that the relevant section of transcript could be referred back to as required (Sanders 2003). In some cases the significant statement was a sentence or a few words, at other points it was more pragmatic to extract a paragraph or exchange of several comments where the content continued to flow. Where researcher questioning was present or sections of irrelevant text the following (.....) was used to indicate the breaks in content.

***"Formulating meanings"* (Colaizzi 1978: p59)**

Participants described their experiences from the perspective of their overall lifeworld; however data analysis requires a transformation of the participant's everyday language into clarified terms relevant for scientific inquiry (Giorgi 1997). This is because the research may go beyond the language used by the participants to express the essence of the phenomenon under study (Todres 2005). This step

therefore requires each significant statement to be rewritten as a 'formulated meaning(s)'. Each significant statement was arranged in the left hand column of a table in the Word document with a column to the right for recording the 'formulated meaning'. Each statement was then studied carefully to determine a sense of its inherent meaning referring continually to the original transcript in order to contextualise the statement within the whole experience (Sanders 2003). Imaginative variation was utilised at this point to question the data to understand what was truly essential about them (Giorgi 2010). Each 'formulated meaning' was then written next to the original significant statement and given a new code based on the interview number and formulated meaning number so that an auditable trail was maintained (Sanders 2003) (for example see Appendix 19).

It is essential that during this phase the formulated meanings stay true to the data. This was achieved through phenomenological reduction in the form of bracketing. My thoughts and feelings were recorded in my reflective diary, this helped to retain control and organisation of my thought processes during data analysis. I also revisited the bracketing interview conducted prior to data collection to remind myself of my own assumptions and feelings about the research focus in order to recognise them and set them aside (Sanders 2003). Once the formulated meanings were completed for each interview they were compared back to the original transcripts to ensure they represented the participants' experiences.

Peer review was requested during this stage of the analysis. An experienced qualitative researcher (CC) reviewed an unannotated transcript and highlighted relevant sections, providing an alternative perspective to encourage further depth of thinking and interpretation. This was also important to ensure that my process was

robust, that I was not distorting the participants' meaning in generating formulated meanings and that my decision making was clear and auditable.

'Organise the aggregate formulated meanings into clusters of themes'

(Colaizzi 1978: p59)

In this stage of the analysis Colaizzi (1978) recommends that the formulated meanings are reviewed to identify if any naturally cluster together and to consider them in relation to the research aim and objectives. Transcripts and recordings were referred to as required to help contextualise the formulated meanings. Some formulated meanings appeared in several themes. Originally I planned to manually move each formulated meaning into theme clusters in a new Word document or through the use of post it notes and flip chart paper. However due to the large number of formulated meanings arising from the data (n=1241) it was difficult to manage using either of these approaches. Therefore first, the formulated meanings were reviewed and duplications in content were removed. The remaining formulated meanings were then printed out as a list and each one was reviewed and coded. During this process the concepts arising from the data were recorded using a concept map on A3 paper in order that they could be easily visualised. Once all the formulated meanings were coded and all the concepts documented, the concept map was reviewed and the concepts further reorganised into emerging subthemes for greater clarity (see Appendix 20).

At this stage a meeting was held with my supervisor (CC) for peer review of the process and for in-depth discussion of the concepts arising from the data and initial thoughts of emerging themes. At this stage it was agreed that there were three emergent themes from the data: "altered relationship with food", "the need for patient centred care" and "relationships with healthcare professionals". A large amount of

data pertained to the more functional aspects of the experience e.g. occurrence of symptoms and the process of line insertion and, whilst the volume of this type of data might suggest that a specific theme may be necessary, the inherent meaning of the descriptions fitted within the other themes described. The process of peer review discussion enabled the distinction to be made between what happened in the experience and the inherent meaning i.e. *how it made them feel*. This is because to achieve understanding in phenomenological research, "one is present not to the words in themselves, but to the meanings given through the words" (Todres 2005: p111). Following the peer review discussion I reviewed the relationship between the different concepts further and revisited the data numerous times to assess if the themes were compatible with the original descriptions given by the participants. The three themes that had emerged were then explored further using imaginative variation to confirm that the themes represented the essence of the experiences reported (see Appendix 21). Three themes were developed from the data analysis process – 'the altered relationship with food', 'the need for patient centred care' and 'relationship with healthcare professionals' with seven subthemes (coping with the inability to eat 'normally', loss of control over food-related decision making, being heard, empowering the patient, competency, trust and coping with poor team working). These are illustrated in the final concept map (Appendix 22).

***'Exhaustive description'* (Colaizzi 1978: p61)**

In this stage of the analysis Colaizzi (1978) advocates that summaries are written for each of the themes. This synthesises the transformed meaning units into a consistent statement of the invariant themes that are reflected in the different experiences (Todres 2005). These summaries will be presented in the next chapter. In order to continually link back to the importance of the participants' descriptions of

their experiences quotations from their narratives will be used during the exhaustive description in order to expand upon the themes with 'real world examples' (Todres 2005). The overarching themes and exhaustive descriptions give structure to the experience but also allow a range of possibilities that allow for the unique variations in each participant's individual experience (Todres 2005).

***'A statement of identification of its fundamental structure'* (Colaizzi 1978: p61)**

This final stage involves formulating an exhaustive description of the investigated phenomenon as a statement of its fundamental structure. The next chapter – results and discussion – represents this type of exhaustive description and facilitates an in-depth understanding of the fundamental structure of the phenomenon being explored in this study.

***'Returning to each subject and....asking the subject about the findings thus far'* (Colaizzi 1978: p61)**

Colaizzi (1978) suggested a final validating step that could be achieved by returning to each participant in an interview setting to ask their opinion of the findings. In this study this strategy was not possible as the recruitment process had been lengthy and due to the time that had elapsed between the first interview and completion of the data analysis it was not practical to further involve the participants. However, Colaizzi's approach to data analysis is flexible and can be adapted to the circumstances of specific studies. Holloway and Wheeler (2010) suggest that findings can be reviewed with the participants at an earlier stage in order to ensure that preliminary interpretations accurately reflect each individual's experience. Giorgi (2009) asserts that to present the participants with the overall findings can be misguided as participants describe their experiences from the perspective of the

natural attitude, are unfamiliar with phenomenology, and may misunderstand the approach – the phenomenological attitude – adopted by the researcher.

Participants were, however, involved in a form of member checking in this study. Copies of unannotated transcripts were sent to the participants asking them to confirm that the transcript reflected the interview conducted and to provide them with the opportunity to comment. The seven participants who took part in member checking confirmed that the respective transcripts reflected the interview and they had nothing else to add.

Chapter 6: Results and Discussion

6.1 Introduction

The aim of this study was to explore the patient experiences of receiving parenteral nutrition (PN) in an acute teaching hospital. Phenomenological analysis of the data revealed three core themes and seven subthemes (see concept map, Appendix 21):

- Theme 1: The altered relationship with eating (Subthemes: coping with the inability to eat normally and loss of control over food related decision making)
- Theme 2: Relationships with healthcare professionals (Subthemes: competency, trust and coping with poor team working)
- Theme 3: The need for patient centred care (Subthemes: being heard, empowering the patient)

The results and discussion have been combined into one chapter in order to avoid repetition and assist the reader. The three themes will each be presented as an exhaustive description in keeping with Colaizzi's method (Colaizzi 1978) utilising quotations from the participants' narratives to illustrate key points. Each exhaustive description of the themes will then be discussed in relation to current research literature.

Each participant account of their experience of receiving PN was unique, shaped by the aetiology of their intestinal failure, the resulting symptoms, the duration of PN required and whether complications were experienced (for participant profile see Appendix 4). The participants all considered PN contributed positively to their lives. They described it as a 'lifeline', 'lifesaving' and stated that it was unlikely that they would have survived without the provision of PN:

All I knew was they were going to feed me and at least I wouldn't starve to death ('Thomas'[11] Interview 1, page 29, line 17)

All participants required the insertion of a central venous catheter (CVC) to provide a route of access for the PN solution. This took the form of either a non-tunnelled multi lumen CVC or a tunnelled single lumen CVC. Many participants required several CVCs due to infection, dislodgment or occlusion. PN was required when the gastrointestinal (GI) tract was incapable of adequate nutrient absorption; this change in GI functioning and the impact this had on the ability to eat is described in the first theme.

6.2 Theme 1: The altered relationship with eating

This theme describes how being unable to consume a 'normal' diet affected the participants and the loss of control over dietary choices they experienced during their hospital admission.

6.2.1 Coping with the inability to eat normally

The change in ability to eat 'normally' was a profound and complex issue for patients who required PN. The symptoms that arose from the altered gastrointestinal function varied according to the aetiology of the intestinal failure but could include nausea, vomiting, pain, diarrhoea and high ostomy[12] or enterocutaneous fistula[13] output. There was no single dietary approach for patients requiring PN with individual recommendations varying from nil by mouth (NBM), low residue[14], liquids only, to a high calorie diet depending on symptoms and anatomy. Some patients

[11] Pseudonyms are used throughout this chapter to protect the identity of the participants
[12] Ostomy refers to a surgical opening of the bowel that is formed to permit the excretion of waste products from the body. The consistency and volume of the ostomy output is influenced by its position in the gastrointestinal tract.
[13] An enterocutaneous fistula is an abnormal tract that forms between the gastrointestinal tract and the skin. It results in a discharge of bowel fluid, the volume of which is determined by the size of the fistula and its position in the gastrointestinal tract
[14] Low fibre

required enteral tube feeding[15], either as a trial prior to commencing PN, or as a transition phase between PN and eating. Eating was a fundamental part of the lifeworld prior to the events that led to PN being required. The changed health status, the altered gastrointestinal function and the need for PN significantly changed this. For some, this was a gradual deterioration in health leading to hospital admission, for others ill health was sudden in onset:

> *We used to enjoy going out for meals and we used to go on cruises and have big meals and things like that, then all of a sudden, you can't eat anything* ('James' Interview 5, page 8, lines 9-10)

Being attached to PN and being unable to eat without the occurrence of significant GI symptoms made participants feel different to other patients in the current social environment of the hospital. Observing other patients eating meals on the ward resulted in feelings of isolation. In addition to this, participants reported feelings of anxiety about eating once discharged from hospital and concern about being able to integrate socially once more. This was particularly pronounced in cases where the changed gastrointestinal function was likely to be chronic in duration.

Although PN was recognised as being life saving and provided relief that nutrition was being given, it did not substitute for eating. The very act of eating was associated with being well and getting home *"if I could eat then I can get better"* ('Susan' Interview 6, page 9, line 26). Eating a 'normal' diet again without the presence of gastrointestinal symptoms was the goal for participants', signifying being well, this was irrespective of whether daily requirements for nutrition were being received from parenteral nutrition. However, participants frequently felt fearful of eating due to the symptoms that it provoked.

The physical impact of being unable to eat normally manifested as weight loss, and a reduction in strength and functional ability. Body weight was a major source of

[15] Refers to liquid feed being provided via a feeding tube inserted into the gastrointestinal tract

anxiety with many participants having lost significant amounts of weight prior to starting on PN due to being unable to eat adequately. The terms 'skeletal' and 'stick thin' were commonly used descriptions of the change to self image:

> *I lost the weight initially through not eating and being sick all the time and, its, you know, to look at yourself in the mirror and just see, you know, a skeletal version of yourself is just horrible* ('Rebecca' Interview 4, page 8, lines 18-21)

The participants in this study did not report that the presence of the CVC was particularly distressing, however, a majority discussed at length the procedures surrounding insertion and removal of the CVC. Some participants found the procedures painful and distressing whereas others found it interesting and were fascinated by the process. All the participants found being attached to the PN feed solutions for long durations tiresome and felt less restricted when the feeding hours were reduced. PN, through its method of administration into the bloodstream, provided relief that eating was not necessary for survival. However for some, PN and being unable to eat signified a change to their self identity, it highlighted that they were ill, and there was a desire to hide it from visitors due to concerns about the social acceptability of being artificially fed:

> *I used to hate having to see people, see me with it [PN], 'cause it, it made, it made me look like I was really frail and ill* ('Sunita' Interview 7, page 11, lines 19-20)

Intestinal failure and its consequences were associated with an altered self-identity. The consequences, such as nasogastric tube insertion for gastric drainage, abdominal drains to allow infected collections to be treated, and the presence of stomas or enterocutaneous fistulae result in bodily fluids being expelled from the body in an altered way. Food directly affected the volume and consistency of many of the bodily fluids being expelled so an association was formed between eating and

these adverse GI affects. The embodied self had changed during the hospital admission and the way that the body dealt with food had altered:

> *[I was] just losing everything I guess, erm, just kind of not absorbing anything and, everything I did drink or eat was coming straight out [of the stoma], so I wasn't getting any benefit from it* ('Rebecca', Interview 4 page 15, lines 10-11)

In addition, CVCs were also required to allow for PN to be delivered into the bloodstream:

> *Well you can see it [central venous catheter].....and you can feel it, it's just an alien thing, you know, having something in your vein, I mean you get used to it obviously, erm, but for me having the stoma as well, there's a lot going on* ('Rebecca' Interview 4, page 7, lines 7 – 8)

PN enabled the malnutrition to be treated which was identified as being of great importance; the gradual improvements in body weight and functional ability boosted feelings of self worth and reassured them that they were making progress in their recovery:

> *Gradually I started noticing that my strength was coming back 'cause I was able to do things on my own, be a lot more mobile, walk about, 'cause I think initially at the beginning I wasn't able to move, walk about on my own or anything* ('Sunita' Interview 7, page 11, lines 27-29)

Despite having a strong desire to eat, being on PN reduced the worry about being unable to eat 'normally'. Knowledge that nutrition was being received, albeit via the bloodstream, enabled participants to cope with this altered ability to eat:

> *Whilst you are on TPN you don't feel as hungry..... when you actually have TPN it takes off that need, that edge..... It wasn't as if you were being withheld your lunch..... Because you kind of knew you were getting it* ('Sarah' Interview 10, page 23, lines 22-27)

Despite the desire to be able to eat normally many participants adjusted to their changed circumstances and became used to the new regimens; they came to terms with not eating or being on dietary restrictions and acknowledged that this was necessary to control their gastrointestinal symptoms:

> *In the end I just resolved myself to the fact that I couldn't eat, 'cause if I did try and eat, this vomiting would start again, it was horrible, I mean for an hour one day.....it was just solid vomit and..... I was filling bowl after bowl after bowl.....and I used to lie in bed and think I'm never going to eat again, never going to go out for a meal, and, in the end I just resigned myself to the fact that the TPN will keep you alive and it's no good trying things that are going to make you ill* ('James' Interview 5, pages 9-10, lines 31-2)

Having PN helped reduce the anxiety of struggling to eat by providing reassurance that nutritional needs were being met. However, periods where PN was interrupted e.g. delays in CVC reinsertion, were traumatic due to the awareness that they were unable to tolerate sufficient amounts of food by mouth to survive, and anxiety that the nutritional progress that had been made due to the PN would be reversed:

> *For that time you're not on TPN, so that's a whole week without any food basically.....I didn't kind of want to end up losing loads and loads of weight again..... it does set you back a huge amount actually that time.....because that's kind of integral for your recovery* ('Rebecca', Interview 4, page 21-22, lines 32-4)

Literature relating to being nil by mouth due to gastrointestinal disorders is sparse. However, there is recent research relating to experiences of eating post bowel resection and eating with chronic gastrointestinal symptoms. McCorry et al. (2009) explored the experiences of twelve oesophageal cancer survivors and ten carers in a qualitative study using focus groups. All the survivors had undergone oesophageal resections to treat their cancer. Three themes emerged from the data: coping with a death sentence, adjusting to and accepting an altered self, and the benefits of peer support. The second theme relating to an altered self particularly resonates with the experiences of participants in this study. The authors described how participants had altered sensory cues related to gastrointestinal function following their surgery and that they had to "learn" the right amount of food to eat in order to prevent vomiting as they were unable to rely on normal bodily triggers such

as hunger and satiety. The changed eating behaviours affected participants personally and socially, due to having less control over their body in relation to eating and the common occurrence of choking and vomiting. Wainwright et al. (2007) explored the experiences of eating post-oesophagectomy in an earlier study in which they conducted semi-structured, in-depth interviews with eleven patients. Interestingly, in this study the importance of maintaining or increasing body weight was identified as being important to many patients as a way of returning to "normal" and as a means of rejecting the identity of illness (in this case that of a terminal cancer patient). The authors described the change to embodied sensations of hunger, satiety, swallowing, taste and smell as a consequence of the oesophageal surgery resulting in the "previously taken-for granted experience of eating [becoming] unfamiliar and alien" (p759). A process of "remapping" is described, an adjustment period, where understanding was achieved about the change in embodied sensations, and patients learned about what and how much food could be tolerated again. During this phase a "tension" existed between the desire of the individual to eat normally and the "limitations of their post surgery body" (p766). The themes described by Wainwright et al. (2007) relate to the findings of this study in several ways. Weight loss was highly significant to the participants as it was associated with ill health, being able to gain weight once on PN was described as an indicator of becoming more well. Participants' also experienced embodied changes to the sensation of eating, particularly relating to alterations in appetite and taste, some of which were very pronounced. In addition, participants in Wainwright et al's (2007) study who required PN described aspects of 'learning to eat again' as they adjusted to their altered gastrointestinal function and their new tolerances to food and fluid.

The participants frequently discussed the body image changes they experienced particularly in relation to the presence of an ostomy [stoma] or enterocutaneous fistulae. The psychosocial effects of PN have been recorded as far back as 1979 (Price and Levine 1979) and there are numerous publications related to the alteration of body image and self identity attributable to other chronic illness or surgical procedures (e.g. Clarke et al. 2008, Coffey et al. 2009, Fingeret et al. 2010, Kelly 1992, Partridge and Robertson 2011). In this study there was little discussion of the surgical incision or scars, the participants' main concern focused on the physical consequences of intestinal failure and malnutrition e.g. severe weight loss, and the changes in relation to control of the excretion of bodily fluids e.g. nasogastric tubes for gastric drainage, ostomy bags to control stoma or enterocutaneous fistula outputs. Thorpe, McArthur and Richardson (2009) explored the experience of bodily change following stoma formation by conducting a qualitative interpretive synthesis of the current research. Eleven research papers were included in the synthesis which led to three broad themes being described: 1) Loss of embodied wholeness: the embodied self has previously been defined as an inseparable union of body and mind: "I am not in front of my body, I am in it, or rather, I am it" (Merleau-Ponty 1962: p150). The loss of embodied wholeness creates a "negative focus on the body, a sense of alienation from the body, the objectification of the body as something that is no longer part of the subjective self" (Thorpe, McArthur and Richardson 2009: p1783). 2) Awareness of a disrupted lived body: becoming aware of the change to the bodily image. This included the perceived need to alter the choice of clothing worn, being aware of the requirement to defecate in an altered manner, poorly fitting and leaking stoma appliances, loss of control over bodily functions and changed bodily sensations. 3) Disrupted bodily confidence: "the disruption to the sense of

embodied self and lived body engendered by stoma formation is likely to change powerfully the relationship between the individual and their 'lifeworld'" (Thorpe, McArthur and Richardson 2009: p1785). This manifested as anxiety that others may be able to see the stoma bag, that the stoma may produce excess effluent or the bag leak at an ill-opportune moment, and about the changed relationships with intimate partners. The authors concluded that living with a stoma impacts significantly on the embodied self, and the person's sense of embodiment within their lifeworld. In this study, six of the ten participants had either an ostomy (stoma) or an enterocutaneous fistula, all of which had been formed or occurred during the current hospital admission. The participants described them as being difficult to manage with frequent leakage due to the high volumes of intestinal fluid being lost as a consequence of their intestinal failure and their experiences are congruent with Thorpe, McArthur and Richardson's (2009) description of "disrupted bodily confidence". The experience of the "loss of embodied wholeness" for PN patients was not only affected by the presence of an ostomy or fistula, but was also significantly affected by the physical consequences of the intestinal failure induced malnutrition.

Living with chronic gastrointestinal symptoms was explored in a descriptive phenomenological study of nine patients with gastroparesis[16] using in-depth interviews (Bennell and Taylor 2013). The predominant symptoms experienced by participants were nausea and vomiting which resulted in altered eating patterns and depression. The authors described the psychological impact of living with gastroparesis and the feelings of loss, isolation and rejection due to the changed behaviour around food and mealtimes, five of the nine study participants had jejunal

[16] Gastroparesis is a condition of delayed gastric [stomach] emptying

feeding[17] tubes so were reliant on artificial feeding. Although there were some similarities between the participants' experiences of upper gastrointestinal symptoms in Bennell and Taylor's (2013) study and those of the participants' in this study who required parenteral nutrition, the underlying aetiologies differed e.g. for the participants requiring PN their symptoms were due to obstruction or ileus rather than gastroparesis. However, despite the differing aetiologies, participants in both studies described very similar psychological impacts associated with their symptoms. Winkler et al. (2010b) described the changed meaning of food and eating in patients requiring home parenteral nutrition (HPN). One of the patterns of eating these authors described - 'eating for survival' - was also identified by the participants in this study both prior to, and after, commencing PN. This pattern of eating was characterised by cycles of trying to eat but having to deal with the consequential gastrointestinal symptoms which Winkler et al. (2010b) identified as ultimately leading to malnutrition, depression and poor quality of life. Participants in Winkler et al's. (2010b) study reported that being able to eat [albeit for some this was a small amount] did bring feelings of pleasure and enhanced QOL, particularly relating to participation in social activities. This is in contrast to this study, where very little satisfaction was associated with eating in the acute care environment. The participants did have a high prevalence of GI symptoms which may reflect the more acute nature of their intestinal failure, however they were also very limited in their food choices due to the catering provision at the hospital. Both the gastroparesis (Bennell and Taylor 2013) and the HPN (Winkler et al. 2010b) studies described the social impact of the symptoms and subsequent dietary restrictions. In this study, the social impact of the altered ability to eat was important to the participants, but was

[17] Jejunal feeding involve the placement of a feeding tube directly into the small bowel (jejunum) to enable nutrients to be delivered into the gastrointestinal tract but bypasses the stomach

different to that reported in the other studies (Bennell and Taylor 2013, Winkler et al. 2010b). Although the hospital environment was not particularly conducive to eating the participants wanted to achieve as normal a pattern of eating as possible. Orrevall et al. (2004) investigated the experiences of oral nutrition prior to the initiation of PN in patients with advanced cancer and reported similar findings. Their qualitative study involved semi-structured interviews conducted with thirteen patients and eleven family members. They found that the period prior to commencing PN to be a time of desperation, chaos and significant weight loss due to the patients trying to eat and being aware of the importance of eating, but being unable to due to a variety of factors including nausea, lack of appetite, swallowing difficulties, gastrointestinal dysfunction and changes in smell and taste of food. This study also captured the perspective of family members who reported feelings of powerlessness and frustration that they were unable to get their loved one to eat. A significant social impact was identified: family roles were altered due to others being required to take the lead in preparing food, and mealtimes were no longer pleasurable for either the individual or the rest of the family, which was distressing to all. It was reported that physicians seen during hospital visits were not particularly concerned with the changes to the oral intake and did not provide advice on how to deal with the problems. Similarly, dietitians provided little more than common sense advice regarding types of foods to consume.

Stern (2006) described three HPN case studies that focused on the psychological impact of nutrition and identified the fundamental role that nutrition has from birth, the parental focus on feeding and elimination behaviours, and the association of food with reward and punishment. These are closely associated with the social aspects of eating that become apparent at an early age, from shared

meals around the family table to celebrations of life events, such as, birthdays. He goes on to describe that when it is not possible to eat “normally”, numerous psychological and social “losses” occur, including the pleasure of consuming food and drink, the social and sensual aspects of eating with others, the nutritional value gained from food and drink, and a loss of independence. Stern (2006) identified eight key features that indicate that a patient may have a poorer ability to psychologically cope with PN:

1. A hatred of the illness or inability to come to terms with the diagnosis or surgery especially when a sense of injustice is perceived
2. Pending court case against a doctor or Trust relating to the care provided
3. No opportunity for psychological preparation in anticipation of the surgery or commencement of PN
4. Past history or predisposition to acts of deliberate self harm
5. Functional bowel disorders with increasing recourse to surgery for essentially psychosomatic complaints
6. Substantial mental impairment including learning difficultly, mood and personality disorders
7. Gender differences in relationship with their bodies – however it is unclear if either gender is more able to cope
8. Demonstrates excessive obsessional traits

The first and third key features were reflected in the participants’ accounts in this study but the degree to which they influenced their ability to cope with the altered relationship with eating and PN is unknown.

Abayomi, Kirwan and Hackett (2009) explored dietary advice and changes to diet by women following pelvic radiation for cervical or endometrial cancer. They used a questionnaire (response rate 87.2%) to assess the incidence of chronic radiation enteritis[18] (CRE) symptoms: 47% of the sample (n=95) had symptoms of CRE. Numerous changes to the diet were reported to control bowel symptoms e.g. eating less food, avoiding food at certain times of day, eating less fruit and vegetables, eating less cereal fibre and eating less fat. Forty seven percent reported changing their diet, which was positively associated with CRE score[19] (p=<0.001). This suggested that those with more severe symptoms were more likely to manipulate their diet in order to control or avoid symptoms. Interestingly, those who had modified their diets saw little improvement in their symptoms, the biggest impact on improving symptoms was through the use of anti-diarrhoeal medication (p=<0.001). Forty five percent had received advice from a dietitian and although dietary manipulation had little reported benefit, those patients who had seen a dietitian were more likely to be taking regular anti-diarrhoeal medication (p=<0.05). These findings are similar to an earlier study (Sekhon 2000) in which a high proportion of patients with chronic gastrointestinal symptoms due to CRE restricted their diets due to perceived food intolerance with little benefit in clinical symptoms. These research findings are relevant to this study as they also indicate the relationship that is formed between gastrointestinal symptoms, food ingestion and appropriate use of medication.

[18] Chronic radiation enteritis (CRE) is caused by damage to the gastrointestinal tract due to radiation treatment. Symptoms can include nausea, vomiting, cramping, diarrhoea, rectal pain, rectal bleeding and faecal urgency

[19] CRE score was calculated based on participant responses to the questionnaire with a higher score associated with more severe symptoms of CRE

6.2.2 Loss of control over food related decision making

Due to the complex aetiologies and consequences of intestinal failure and the changed relationship with food, participants lost confidence in knowing what food choices to make. Many were scared that they would eat the wrong thing and it would adversely affect them. Their previous 'normal' diet was frequently not tolerated due to the changed gastrointestinal functioning. Participants received dietary advice from multiple healthcare professionals, on what they 'should' be doing, which was often conflicting. This undermined their self confidence in making food choices based on their *own* experience of gastrointestinal symptoms. As a result, the participants wanted more guidance on what to eat according to their gastrointestinal symptoms and for some this led to a desire for an individualised, prescriptive diet:

> *It would be better to have a personalised diet plan rather than a mark yourself off.... it's alright if you.....don't have erm, a digestive problem, just to tick things off, but.....if you've got a disorder of your bowels, that is not right, the patient doesn't know, I didn't know what I couldn't eat or what I couldn't have or what I should have.....I didn't know, it was, it was more by luck than judgement and it didn't work in my case, the guessing – I didn't guess right* ('Steven' Interview 3, page 17, lines 16-22)

Daily calorie targets for eating had been given to several participants. For some these were motivating and provided some control, especially when associated with a specific benefit e.g. being able to stop PN and be discharged home. However, for others it created a pressure to eat more, resulting in anxiety that the targets were not achievable. Participants found that eating, particularly when associated with poor appetite, could become a source of conflict between them and both healthcare professionals and family members. Pressure to achieve calorific targets could be counterproductive due to the increased anxiety at not achieving goals:

> *I think being told, you need to eat 3000 calories a day, when you're not hungry..... I'm quite conscientious in terms of wanting to do what, the best I can do to make myself better, I've always tried to do what I've been told..... I would dread mealtimes.....because I knew that I'd have this guilt battle with myself that I didn't want to eat it and, its, for me, like I'm a massive foodie as well, like I've always eaten really really well* ('Rebecca' Interview 4, page 8, lines 23-27)

In order to try and achieve prescribed calorific targets many participants reported having to force themselves to eat, resulting in a loss of enjoyment associated with eating. The act of eating itself could be physically and emotionally draining and exhausting. Equally when restricted to only certain types of food this could lead to periods of poor adherence to dietary advice with participants reporting that, at times, they did consume meals that were against the recommended advice in order to experience enjoyment from eating, while acknowledging that there may by consequences in terms of gastrointestinal symptoms.

Barriers to achieving calorific targets, when established, included having a poor appetite, taste changes, the hospital environment being unpleasant and not conducive to eating and inadequate provision of suitable foods to allow goals to be met. Participants reported trying to overcome these barriers:

> *I ended up doing was going into the.....day room, erm and having my food in there because it just kind of felt like I was moving away from all the kind of medicalness of it.....because you, you're.....surrounded by poorly people aren't you and you're one of them and.....you wouldn't normally eat in places like that* ('Rebecca' Interview 4, page 14, lines 20-24)

In the participants' experience dietary recommendations were not well communicated by healthcare staff and they were relied on to alert catering staff to food restriction changes. They found this responsibility difficult to achieve as during each day various clinical teams visited and the advice they were given could change several times. The participants clearly identified the poor presentation of hospital food and the limited choice available to meet their dietary needs as significant

barriers to eating. Hospital food was described as unappetising due to lack of flavour and frequently being served cold. The requirement to order food on the day prior to consuming it was also a significant barrier to eating, especially when dietary allowances and/or restrictions were frequently altered but not communicated between healthcare staff:

> *They wouldn't change what was on my board so, the dinner people would come round and say "no, it says you can't eat" and I would say "I was told this morning that I can* ('Sarah' Interview 10, page 5, lines 19-21)

Dietary restrictions were difficult to follow as they differed from their usual dietary intake. Not only were the types of food being offered different, but the restrictions meant that there were less choices of food as would have normally been possible as part of their diet:

> *When I was advised to stay to a low residue diet, 'cause I'm a big salad and vegetables person and I was told to stay away from all of that, so, its, it's kind of, being, being told you've got to eat what you don't really want to eat* ('Rebecca' Interview 4, page 8, lines 11-13)

Participants often felt considerable pressure to eat their "new" diets in order for the PN to be discontinued; however the type of diet and the unfamiliar hospital food was "alien" and difficult to adjust to.

Many participants endured a period of time, whilst on PN, where they were advised not to consume any food. Being restricted from eating food had a significant impact on the individual e.g. *"Being told to not eat is like having a hobby taken away"* ('James' Interview 5, page 8, lines 6-7), especially when the rationale for the advice was not understood:

> *For me..... the lowest point was, when I had to come onto the TPN and I wasn't allowed to eat, that..... psychologically that really messed me up, 'cause, I didn't realise.....how I could survive without.....eating* ('Sunita' Interview 7, page 26, lines 12-13)

To support a discussion of this subtheme the literature related to appetite and behavioural influences on diet was explored. Self determination theory proposes that behaviour change is dependent on underlying motivation (Deci and Ryan 1985) and has been used to underpin numerous studies in healthcare, particularly relating to back pain, (Murray et al. 2015), weight management (Silva et al. 2010), smoking cessation (Choi, Noh and Park 2014), cardiac rehabilitation (Sweet et al. 2014) and diabetes (Austin et al. 2011, Williams et al. 2009). Two main regulation styles for eating behaviours have been described in the literature (Otis and Pelletier 2008); autonomous and controlled regulation. Autonomous regulation refers to "engaging in the regulation of eating behaviours out of a sense of choice and responsibility" (p55), within the context of PN this would relate to those who choose to follow dietary advice in order to achieve the goal of symptom improvement e.g. for reduction in stoma / fistula output. In contrast, controlled regulation is "performed out of pressure from oneself or others" (p55) relating to those following advice because they are "told to" by healthcare professionals, or those trying to eat more due to pressure from family members. Autonomous regulation has been linked to beneficial outcomes whereas controlled regulation is linked to negative outcomes in healthy participants, in those who are severely obese, and those at risk of coronary artery disease (Hagger, Chatzisarantis and Harris 2006, Williams et al. 1996, Pelletier et al. 2004, Pelletier and Dion 2007). Otis and Pelletier (2008) suggested two orientations to food planning - approach and avoidance – that mediate these regulation styles. An approach orientation focuses on moving towards desirable objectives e.g. less vomiting, weight gain whereas an avoidance orientation focuses on undesired objectives e.g. not being able to eat a particular food. Those with approach orientations are more likely to see progress towards goals and be more positive

(Elliot, Sheldon and Church 1997). It can be hypothesised that utilising approaches that encourage autonomous regulation and an approach orientation may facilitate more positive eating behaviours in other patient groups including those requiring PN but there is currently no literature to support this hypothesis.

In Maslow's (1943) *Theory of Human Motivation* a hierarchy of needs is described with the satisfaction of hunger and thirst being a core component at the first level: physiological needs. Maslow's theory suggested that when the needs of the lower levels of the hierarchy are not met, the higher levels are not achievable. For patients who require PN who not only have an altered gastrointestinal tract but are also receiving PN as their main source of nourishment the disruption can be profound. Earlier research (Sriram, Pinchcofsky and Kaminski 1984, Charuhas et al. 1997) suggested that PN can have an inhibiting effect on appetite, however, many patients who require long term PN do report persistent feelings of hunger suggesting that any appetite modulation effects may be only partial (Stratton and Elia 1999). As in this study, many patients requiring PN are able to consume some food although absorption may be reduced. Due to the diverse aetiologies of intestinal failure and the associated symptoms patients' oral intake can also be extremely varied. There will also be numerous other influences on appetite e.g. gastrointestinal symptoms and being in an environment conducive to eating. These represent potential barriers in the acute care environment where GI symptoms are often more pronounced, food is less desirable, and the social environment for eating is occupied by other patients who may be experiencing unpleasant symptoms such as vomiting or pain. The ability of the gastrointestinal tract to tolerate some nutritional intake (enteral nutrition) is important to achieve, where possible with patients with intestinal failure, as it provides physiological benefits (Nightingale 2001). Enteral nutrition can aid gall

bladder emptying, decrease villous atrophy, reduce the risk of bacterial translocation and promotes adaptation of the gastrointestinal tract (NICE 2006). It is also often promoted because the oral consumption of food can contribute to QOL through improved self esteem, pleasure and enjoyment (Winkler et al. 2010b).

Parenteral nutrition is considered to be a less physiological method of feeding than enteral nutrition[20]. PN is infused as a liquid, typically over 12-24 hours, and thus feeding often continues during periods of sleep. It also bypasses the gastrointestinal tract which normally regulates appetite and food intake (Stratton and Elia 1999). During the normal process of food ingestion the gastrointestinal tract secretes various peptides which affect satiety including ghrelin, peptide YY, glucagon-like peptide 1 and cholecystokinin (Chaudhri, Small and Bloom 2006). The impact that the administration of PN has on the production of these peptides and in appetite regulation is not fully understood. In previous studies on healthy volunteers provision of PN have shown a simultaneous reduction in orally consumed calories (Sriram, Pinchcofsky and Kaminski 1984, Gil et al. 1991). Charuhas et al. (1997) conducted a double-blind randomised trial comparing PN with intravenous hydration on the time taken to resume oral intake in two hundred and fifty eight bone marrow transplant recipients. They found that the time taken to achieve an oral intake of ≥85% of estimated energy requirements was six days earlier in the hydration group in comparison to the PN group ($p=0.049$). This suggested that the provision of PN inhibits appetite and delays the resumption of oral intake. More recently, Murray et al. (2006) explored the effects of three different macronutrient infusions (10% dextrose, 10% fat or mixed protein/carbohydrate) on patient reported hunger levels, satiety and nausea plus plasma concentrations of ghrelin and peptide YY in six

[20] Enteral nutrition can refer to oral diet, ingestion of oral nutritional supplements or provision of an artificial liquid feed directly into the gastrointestinal tract via feeding tube

medically stable outpatients with intestinal failure requiring HPN. Each participant was randomly assigned to receive one of the infusions over a two-hour period following a 12 hour fast. No change in participant levels of hunger or satiety were reported with any of the three infusion types but the authors found that the dextrose and mixed protein/carbohydrate infusions led to a decrease in ghrelin concentrations ($p<0.001$), whilst the fat infusion reduced peptide YY concentrations ($p=0.004$). This may be due to the study conditions not reflecting the standard usage of these types of infusions, which are typically given over a longer durations, with a greater calorific content. Stratton and Elia (1999) reported that 75% of patients requiring HPN felt hungry, with 44% of these being distressed by the symptom. In the acute setting the same authors found that from a sample of twenty eight patients requiring PN, 43% felt hungry, 52% had a desire to eat but only 14% were distressed by hunger (Stratton and Elia 1998). However, interestingly, those who did not feel hunger were typically experiencing an acute phase response indicating an inflammatory state. In this study many of the participants reported poor appetites and difficulty consuming food orally. Whether the provision of the PN solution itself affected their appetite remains unclear. The presence of a reduced appetite during hospital admission may be a physiological adaptive response to being acutely unwell (Davidson and Smith 2007) and needs to be rigorously studied. The provision of PN solution may have a role to play in the anorexia commonly associated with being acutely unwell, however, it seems more likely that this may be the result of a complex interrelationship between a number of factors.

6.2.3 Summary

Patients requiring PN have an altered relationship with eating due to the significantly changed functioning of their gastrointestinal tract. While PN may not substitute for

eating the participants considered it a positive treatment due to it being able to correct the intestinal failure induced malnutrition. Dietary targets were often difficult to follow for patients requiring PN and this could result in feelings of anxiety and loss of control.

The literature explored relating to this theme revealed the impact that gastrointestinal disorders can have on eating, embodied self and well being. This study extends this body of knowledge to those with intestinal failure that as a result requires the use of PN.

6.3 Theme 2: Relationships with healthcare professionals

This theme relates to the contact with, and care provided by, healthcare professionals in relation to PN. Three subthemes were identified: competency, trust and coping with poor team working. Each subtheme will be described in turn and relevant literature then explored. It should be noted that the three subthemes overlap.

6.3.1 Competency

Conflicting dietary advice, particularly when being weaned from PN onto an oral diet, was experienced as confusing and distressing by the participants who reported a strong desire to receive their dietary advice from experts:

> *Having agreed a plan with the nutritionist to have it all upturned by the surgeons team coming round and sort of doing something different is difficult when you're a patient, you're in-between, you're trying to moderate between the two extremes..... I would really suggest that the nutritionists are in control of your diet, directly* ('Steven' Interview 3, page 8, lines 1-3)

One participant recalled how three different clinical teams provided her with different dietary advice within one day and often team members could not agree on the correct diet for her. Participants often received dietary advice from sources that

were not experts on nutrition and they questioned the competence of the individuals involved:

> *That was the dispute really through all of it was, I suffered more as a result of the bad diet advice than the rest of it* ('Steven' Interview 3, page 18, lines 12-13)

Some participants identified that staff lacked the competence to care for PN which was a concern, for example, Rebecca developed a CVC infection following poor handling of her feeding line:

> *The first one I think, erm, we think was erm, a, I think, a nurse who was not usually on that ward flushed it with just a normal flush, erm, and then it was a couple of days later that I got the infection, so, that's potentially what caused that one* ('Rebecca' Interview 4, page 10, lines 25-27)

When catheter related blood stream infections (CRBSIs) occurred the PN had to be stopped while the infection was treated and this had a huge impact on the participants' sense of well being and affected their confidence in the staff caring for the CVC. Participants found it reassuring when nursing staff took time, while carrying out care tasks, to explain the correct procedures for handling the CVC as it demonstrated nursing competence and also enabled them to learn more about how to manage the CVC:

> *She was very very good at sharing the knowledge with the other junior nurses and the student nurses, erm, so it was quite nice, she was talking through the correct, by the book procedures obviously because she was training them, so when another nurse came and did [it] I'd know if they were taking shortcuts* ('Sarah' Interview 10, page 24, lines 11-15)

Participants in this study made it very clear that they wished to receive information regarding their nutritional care from the NST due to the value and trust they had in the team members' knowledge and expertise. National publications also recommend the involvement of NSTs[21] in the care of all patients requiring PN (NICE

[21] Nutrition support teams typically comprise of a lead physician, dietitian, nurse and pharmacist

2006, Stewart et al. 2010) due to the knowledge and experience of PN and intestinal failure that they are able to contribute. The NCEPOD national audit of PN (Stewart et al. 2010) demonstrated that quality of care was substantially improved when PN patients had NST consultation, however, they still found that in >70% cases nutritional care was suboptimal. This audit highlighted the high degree of variation in the composition and function of NSTs within different organisations across England, especially regarding the degree of autonomy over PN related decision making. Measures used to assess the effectiveness of NSTs included the occurrence of complications (CVC related[22] and metabolic), the appropriateness of PN as a treatment and choice of CVC used (Hvas et al. 2014, Kennedy and Nightingale, 2005). However, there is surprisingly little recent evidence in the research literature that supports the effectiveness of NSTs. Furthermore, little attention has been previously paid to the role of eating, which often happens concurrently with PN and the need for advice and support about this aspect of patient care. The participants in this study identified this as a fundamental issue that mattered to them in determining the quality of care provided.

Participants reported that doctors[23] frequently assumed the role of authority regarding nutritional care and expressed concern that they had inadequate knowledge to support the role. Awad et al. (2010) investigated the knowledge of sixty-three surgical trainees (newly qualified doctors, junior level of surgical training and senior level of surgical training) and compared it to that of qualified dietitians (n=25) using a multiple choice question test. Despite 65% of the surgical doctors reporting that they were regularly making decisions regarding nutrition support they demonstrated significantly lower

[22] Including catheter dislodgement, occlusion and catheter related bloodstream infections
[23] From various medical specialities and including all levels of seniority

levels of knowledge on fundamental aspects of nutrition support on multi choice questions ($p<0.001$). This study demonstrated that dietitians have a greater level of knowledge than surgical doctors regarding general nutrition support, however, it does not provide evidence concerning the accuracy and appropriateness of the nutrition advice given to patients. Patients who require PN are, by nature, more complex due to their diagnosis of intestinal failure and the associated gastrointestinal symptoms, however, there is no current research available that investigates surgical doctors' competency in providing dietary advice to this complex patient group. This study suggests that surgical doctors lack the knowledge necessary to give correct dietary advice to patients with intestinal failure. This is particularly highlighted by the participants' comments about the differing information given by surgical teams particularly when compared with the advice provided by the NST. A key example of failing to provide patients with the correct advice is the recommendation of patients to follow a 'light diet'[24]. Several participants reported being told to follow such a diet by surgical doctors when recommencing an oral diet. Scutt and Hellman (2008) explored the use of, and evidence for, a 'light diet' dietary restriction in surgical patients. They found no evidence in the literature to support the use of 'light diets'. A questionnaire was distributed to healthcare workers, in addition to data being collated on the number of surgical patients on dietary restrictions on a single audit day. They found minimal agreement between healthcare professionals about what constituted a 'light diet', despite this, 10% of surgical patients in their sample were found to be complying with this dietary restriction. The

[24] This term historically referred to food such as soup, ice cream and mashed potato due to the perception that they are easier to digest. However interpretation of the term is extremely variable in clinical practice. This has led to more specific, evidence based dietary advice now being used.

authors indicated that the inappropriate use of dietary restrictions remains a component of the postoperative management of surgical patients. There is no research evidence to support these restrictions and unnecessary dietary restrictions will contribute to poorer nutritional intakes. Due to poor agreement on what a 'light diet' includes, implementation of such a diet is likely to be confusing for both patients and healthcare staff. This highlights a key issue raised by participants over the poor guidance provided by healthcare professionals who have inadequate knowledge about what they should eat.

Raman, Violato and Coderre (2009) investigated the nutritional knowledge of gastroenterology fellows[25] (n=32) in Canada, by conducting a questionnaire to assess perceived knowledge, and then by administering a multiple choice question examination to measure knowledge. The main findings were that most (62.5%) gastroenterology fellows had not received any nutrition education during medical school and 31.3% had not yet received any nutrition education during their fellowship. They perceived themselves to have inadequate knowledge in the domains of obesity and micro and macronutrient requirements and nutrition relating to GI disease, with greater knowledge in the areas of nutrition support and nutrition assessment. The mean examination score was 50%. However, no details were provided on the content of the MCQ assessment or any comparisons made with experts in nutrition. This study again highlights areas of concern regarding the nutritional knowledge of doctors who may be assuming responsibility for patients' nutritional care.

[25] Gastroenterology fellowships in Canada are periods of structured, specialist training in gastroenterology

Dietitians are one of the core professions of a NST due to the knowledge they bring of dietary advice, nutritional assessment, calculation of nutritional requirements and knowledge of enteral and parenteral feeding products. In a qualitative study, Endevelt and Gesser-Edelsburg (2014) conducted focus groups with patients who had clinical interactions with dietitians in order to explore the approach taken in the provision of education and counselling in establishing nutritional care plans. They found that those patients who reported receiving a standardised rather than individualised educational and informative approach to advice were discouraged from adhering with treatment. Those dietitians who took a more therapeutic approach and related advice to individual needs were more likely to achieve sustainable results. Endevelt et al. (2013) investigated whether nutritional counselling by a dietitian contributed to weight reduction in patients (n=1680) who had undergone bariatric surgery. Those patients who received dietetic counselling at least twice (28%) were significantly more likely to achieve a BMI reduction of at least 5% (p=0.04). However, it is unclear whether these results reflect the skill of the dietitian or the motivation of the patient group that attended for follow up in Endevelt et al's (2013) study. Thompson et al. (2003) conducted a systematic review of twelve studies to assess the effects of dietary advice given by a dietitian compared with another health professional or self help resources in reducing blood cholesterol levels in adults. Dietitians were found to be more effective (4%) than doctors in lowering blood cholesterol in the short to medium term but there was no evidence that they were any more effective than self help resources or nurses. This review was, however, limited by the number, and quality, of the studies included. These studies

suggest that when taking an individualised approach, dietetic interventions can enhance the achievement of nutritional care goals, however, the research is limited, in addition, these studies reflect dietetic intervention in patients without intestinal failure.

Culkin, Gabe and Madden (2009) evaluated the effectiveness of nutritional advice given to patients with intestinal failure requiring HPN. In this study a written booklet of nutritional advice plus a verbal individualised explanation of the advice was provided by a dietitian to patients (n=48) with intestinal failure. Pre and post intervention evaluation was conducted using a questionnaire, oral nutrition intake (using a 3-day food and fluid record), nutritional status (weight, height, BMI, presence of fluid disturbances, mid arm circumference, tricep skin fold thickness (TST), mid arm muscle circumference (MAMC)), QOL (using SF-36 and EuroQOL questionnaires) and content of HPN solution. They found that patients' knowledge significantly improved ($p=<0.001$), oral energy (calorie) intake improved ($p=0.04$), BMI increased ($p=0.02$) and the requirement for HPN was reduced (PN energy $p=0.02$, volume $p=0.02$, frequency $p=0.003$). No statistically significant change was observed in mean TST or MAMC. This study demonstrated that individualised dietary advice, in conjunction with written information, was able to significantly improve the knowledge of patients with intestinal failure and had a positive influence on patients' eating behaviours and requirement for PN. What remains unknown is what had the greater influence on increasing patient knowledge – the written booklet or the verbal individualised advice given by a dietitian. However, it does demonstrate that providing clear information, tailored to the person's individual circumstances,

positively influences the ability to increase oral intake in intestinal failure patients.

There is limited evidence for the effectiveness of dietitians or NSTs in comparison to other healthcare professionals in general. Provision of nutrition in the context of intestinal failure and the requirement for PN adds a further level of complexity and more detailed understanding and knowledge is needed of the altered gastrointestinal anatomy that influences the required dietary manipulation when introducing enteral nutrition (either oral or via feeding tube) either to wean from PN or concurrently.

6.3.2 Trust

All participants had contact with the nutrition support team (NST) during their episode on PN, however, in many cases this occurred *after* their doctor had told them that PN was required and a CVC had already been inserted for feeding. The NST members were recognised by the participants for their expertise in advising on nutritional care. The participants also considered the team to be likeable and personable, that the team members listened to them, and formed nutritional treatment goals with them. Most participants had high regard for the opinions of the NST describing them as “the experts” and that their advice could be trusted. However, the NST were also observed as being, in some cases, on the periphery of care and that their recommendations did not necessarily translate into the changes to the nutritional care plan that had been agreed. This was particularly evident where surgical teams assumed responsibility for the overall patient care and, under these circumstances, tended to overrule the advice of the nutrition support team. This, however, did not affect the participants’ confidence and trust in the NST advice;

in fact they expressed frustration that the 'expert' advice had been ignored. This highlighted a hierarchical structure within the healthcare provided, which one participant described as:

> *The surgeons and their team.....I don't know, the politics were such that the surgeons said something and everybody else went "yes sir".....I didn't think it was a team, it was an individual with others following..... but the nutritional [sic] was a team, they came round and discussed it, and it was quite, quite good, and the plan was a collective plan that you agreed to, to give you the best of the circumstances, but it couldn't always be followed especially with the food* ('Steven' Interview 3, page 18-19, lines 29 – 6)

Participants reported that the NST communicated well with them:

> *They're always, you know they've talked me through what's happening, they explain that, that this TPN is, is, is made for your body, you know and they have, they have to, they kept weighing me, they have to make it up so it, it suits me and, it's always been explained, I've never felt like I've been left out of the loop* ('James' Interview 5, page 17, lines 8-11)

However, this team, while clearly having the expertise, had not yet built relationships with some patients:

> *The nutritionalist team tells you far more as to why, but they are a new team and they are new people coming in who you might only see every other day and only see three times because if you are only on it a week, your consultant you see every day, you've seen them before ops, usually a couple of times, so there should be a rapport with your consultant or his team* ('Sarah' Interview 10, page 27, lines 22-26)

Having continuity with healthcare staff enabled trust to be established and support to be provided, for example, Sunita was very anxious while undergoing a line removal:

> *I was like "please don't hurt me" and he was like "don't worry..... you're fine, you're fine, you've been through worse, I've been there with you", because he had* ('Sunita' Interview 7, page13, lines 39-40)

Nursing support during procedures was highly valued by participants. CVC removal, in particular, could be an emotional experience as it signified either the end of the need for PN or the presence of an infected or blocked CVC that required removal. Reassurance provided by nurses was comforting:

> *I just started crying and she held my hand, then I started speaking to her and we were just having a normal conversation while all this was going on, me and her were talking and we were just talking about random, right random crap, and I think I was doing most of the talking and she was doing most of the listening* ('Sunita' Interview 7, page 14, lines 6-8)

Where there was evidence of good communication and informative explanation participants felt confident in what was happening and trusted the team members involved:

> *Yeah it was always clear, they always explained what they were going to do, nobody just dived in and started without telling me anything. I always felt like I said, I was in the loop and, they cared for what they were saying and they cared what was going to happen. And I mean I had so many procedures carried out in the hospital but every time the staff that were doing it were so good and it, the thing is, it made, it calmed you down, because if you, you trusted them* ('James' Interview 5, page 19, lines 4 - 8)

Trust is complex and influenced by both the healthcare organisation structure and the individuals that represent it (Mechanic and Meyer 2000). Key factors which have been reported to influence trust in healthcare professionals include: competence, benevolence, integrity, respect, honesty, media and previous experience of healthcare professionals (Meyer 2008). Trust in healthcare providers can enhance shared communication, facilitate patient agreement to treatments and advice, reduce patient uncertainty and anxiety, and result in greater satisfaction with the care received (Meyer 2008, Lee and Lin 2011). Lee and Lin (2011) conducted a one-year longitudinal analysis of 614 type 2 diabetic patients using self administered questionnaires and medical notes to examine the impact of trust on patient outcomes. They found that trust was positively related to better glycaemic control, physical health related quality of life and patient satisfaction. No literature could be found exploring patient trust in nutritional care. Patients who require PN have complex treatment plans involving modification to their diet and fluid intake, medication regimens and provision of the PN itself via CVC. The participants in this

study highlighted that trust in the healthcare professionals providing nutritional care has both positive and negative impacts on the patient experience.

6.3.3 Coping with poor team working

Participants in this study were located predominantly on surgical wards (of which there are several) and the gastroenterology ward (see Appendix 4 for participant profile). At the time of their admission numerous medical/surgical teams[26], representing various medical specialities (e.g. upper gastrointestinal (UGI) surgery, colorectal surgery, oncology, hepatobiliary (HPB) surgery, urology, gastroenterology), were involved in providing care, and each participant was assigned to a team based on their diagnosis and the treatment they required. The NST worked independently from these teams and assessed and reviewed all individuals requiring PN following an initial referral from the primary medical/surgical team. All the participants had contact with the NST, as is a requirement in the hospital where the study was based, whereas the main medical/surgical team coordinating their care differed. Following referral, communication between the NST and the medical/surgical team appeared to be based on written communication in medical notes and through ad hoc discussions (either face to face or via telephone). None of the participants reported the medical/surgical team and the NST providing joint consultations. For the participants, the lack of effective communication and coordination between the teams involved in their care was a significant problem as it led to fragmentation of information and undermined their trust. This caused confusion and anxiety for the participants, particularly when the medical/surgical team gave nutritional

[26] Team members included junior doctors receiving foundation training, doctors undertaking specialist training (at numerous levels) and a leading Consultant in charge of patient care

advice that was in conflict with the advice of the NST. The nutrition service review, conducted prior to this study which was discussed in the introductory chapter, highlighted problems in the coordination of nutritional care within acute care, but failed to include the patient perspective. This 'failure' was one of the clinical triggers that led to this study being designed. Despite this study being conducted several years subsequent to the service review[27], what the participants reported indicates ongoing issues associated with the coordination of nutritional care.

The main fundamental issue, identified by the participants, was the overlapping nature of professional roles within acute healthcare, which was primarily evident when professionals, without the benefit of nutritional knowledge and skills, assumed a leading role in nutrition related decision making. According to Nugus et al. (2010) role boundaries within healthcare teams are actively negotiated and are "dynamic, contextual and negotiated" (p899). In this study, the participants highlighted that the communication and role boundaries within a single team was not problematic – it was the communication and coordination between several clinical teams, particularly the NST and the primary medical/surgical team. An interdisciplinary team working model[28] is advocated for single healthcare teams, and considerable research has been conducted highlighting the benefits to both the patient and to team functioning by adopting this approach over a multidisciplinary team working model[29] (Körner 2010). Although this model cannot be directly

[27] The nutrition service review was carried out in 2010
[28] *Interdisciplinary* teams meet regularly in order to collaboratively set goals and jointly work towards a treatment plan with a high degree of cooperation and communication (Körner 2010).
[29] *Multidisciplinary* team working involves numerous professionals working in parallel, with clear roles and tasks, and a hierarchical line of authority with the physician directing the overall care. Each

applied to the overall service provided to PN patients due to the numerous medical/surgical teams involved, fundamentals of interdisciplinarity could be considered. Team working in healthcare is based on the premise that professionals want to work collaboratively to provide better care to patients (D'Amour et al. 2005). D'Amour et al. (2005) and Martín-Rodríguez et al. (2005) identified the tendency to maintain professional territories as a factor that hinders the development of collaborative relationships and coordinated or seamless service delivery. According to Martín-Rodríguez et al. (2005) "the development of collaborative practice depends on the mutual recognition by professionals of their interdependence as well as acceptance of the 'grey zones' where their respective contributions may overlap"(p136-137). The ability to understand and respect the expertise of other professional roles allows dialogue to be opened on the negotiation of the 'grey areas' and role boundaries. This may be challenging in the context of PN in the acute healthcare setting due to the numerous teams with which negotiation of professional roles would need to occur. Matarese, Jeppesen and O'Keefe (2014) described the clinical issues encountered by patients with short bowel syndrome[30] and the complexities of providing individualised patient strategies in order to maximise health and quality of life outcomes, minimise complications and short bowel syndrome associated mortality. In this review paper the authors asserted that a fundamental component of the management of this patient group is the interdisciplinary team. The authors argue that this approach is required in order to achieve the optimal outcomes for this complex patient group. Despite the limited applicability due to there

multidisciplinary team member creates their own treatment plans and goals depending on their own professional focus (Körner 2010).

[30] A common cause of intestinal failure

not being a single team managing patient care, there are fundamental aspects of interdisciplinary team working, such as, agreeing on shared goals, understanding and respecting other professional roles and expertise, and the negotiation of role boundaries in order to tailor the service provided for specific patient needs.

For components of interdisciplinarity to be successfully utilised in acute healthcare, considerable organisational re-structuring would need to occur in order to facilitate a more streamlined approach to patient care, particularly in complex cases. A significant barrier to effective streamlining of care for PN patients in the study setting is the variety of wards on which PN patients can be located. A potential solution to this could be the relocation of patients requiring PN to a single location where specialised focused nutritional care could be provided, however this would have implications for other aspects of patient care. The distribution of PN patients across the hospital rather than in one clinical area and the numerous primary medical teams involved makes it challenging to focus quality improvement initiatives, such as, improvements to nursing knowledge and skills required for CVC care. The *Strategic Framework for Intestinal Failure and Home Parenteral Nutrition Services for Adults in England* (National Commissioning Group for Highly Specialised Services 2008) made a case for change in the management of patients with type 2 and type 3 intestinal failure. The report focused on those patients who require PN for a prolonged period of time either on hospital wards or in the home environment. The core recommendation of the report was the setting up of a clinical network of English hospitals to establish clinical care that met nationally agreed standards for these patients. In this report the authors

suggested that having a dedicated baseline number of beds for patients requiring PN that locates the patients in one hospital area would be beneficial from a clinical, logistic and psychological perspective. From the reports of the participants in this study this could potentially help improve coordination and communication and their nutritional care. However, this network is not yet in place therefore a number of lower level strategies to facilitate a more integrated patient-centred approach e.g. training of healthcare workers, and initiatives to improve communication between the teams involved, would be more realistic to consider in the shorter term. These implications and recommendations will be discussed in the concluding chapter.

Communication errors, miscommunication and poor coordination are common causes of adverse events in health, cause patients harm and adversely affect the patient experience (Nagpal et al. 2012, Neale, Woloshynowych and Vincent 2001). Brady et al. (2009) conducted a literature review in order to understand the nature and costs of adverse events in healthcare and the potential strategies to reduce or prevent these. They found the nature of adverse events to be diverse, for example, medication errors, infection control errors, patient accidents, documentation errors, and such adverse events "can be attributed to a multitude of individual and system contributory factors and causes" (p 155). These authors highlighted the financial and non financial costs associated with patient adverse events. Financial losses associated with adverse events included an increased length of hospital stay with resultant absence from usual employment, and costs related to medical litigations which can be influenced by the type of harm experienced. Non-financial costs included the increased pain, suffering and

anxiety for patients and the loss of confidence and trust in the hospital. Suggested strategies to reduce adverse events in hospitals included organisational culture changes to encourage reporting of incidents and learning from mistakes (Brady et al. 2009). In addition, the authors highlighted that nursing staff were key to patient safety and that ensuring staff had adequate knowledge and skills and allocated in sufficient numbers would contribute to improvements in patient care. One initiative focused on improving patient safety by developing and implementing approaches that strengthen collaborative relationships between nurses and physicians. The study participants' accounts supported the development of nursing knowledge and skills with PN and the provision of sufficient staff to allow adequate time to provide a high standard of care. However, it was clear that the participants felt it was of primary importance to focus on the collaboration between all the healthcare professionals involved in their care, not solely the nursing staff and physicians.

West (2006) suggested that hospitals, as complex organisations, are vulnerable to breakdowns in communication and coordination due to the tendency of professions to work within their individual professional disciplines. Baines et al. (2013) conducted a retrospective patient record review (n=4,023) using a stratified sample of twenty hospitals in the Netherlands to determine the number of medical specialities treating each patient and whether this was associated with the risk of patients' experiencing harm during the hospital admission. The authors found that compared to patients treated by only one speciality, those treated by three or more medical specialities had an odds ratio of experiencing an adverse event of 3.01 (95% CI 2.09 to 4.34) and with

a preventable adverse events odds ratio of 2.31 (95% CI 1.40-3.81) when adjusted for patient characteristics. They highlighted that communication failures are a common, if not leading, cause of patient harm. The authors argued that, while increasing specialisation in medical care can be beneficial due to enhance knowledge and skills in the speciality, specialisation can also have detrimental effects. These are due to the increased need for coordination and communication between specialities and less access to speciality care outside of core working hours. This study shows that even when teams comprised of a single professional group (in this case medicine) are most commonly responsible for patient care, detrimental effects can still occur and highlights the need for further research to investigate the underlying causes and appropriate preventative strategies. Participants reported more positive experiences of their nutritional care when the NST consultant physician was also their primary medical physician. In their opinion, this resulted in less medical /surgical teams being involved in their care and a more streamlined, coordinated service as there was a direct link between the medical and nutritional care teams.

6.3.4 Summary

In this study the participants described three overlapping subthemes that affected their relationships with healthcare professionals. Competence to care for the PN by the nursing staff was not evident on numerous occasions in the experiences described. This affected the trust in the care being provided. Equally, the provision of dietary advice from healthcare professionals who were not experts in nutrition which often conflicted from the reported expert advice of the nutrition team further damaged the trust that the participants had in the overall care provided by the

organisation. This, coupled with ongoing problems with communication resulted in the participants not being clear on what nutritional plan they should be following and whose advice they should trust.

6.4 Theme 3: The need for patient centred care

Two subthemes contributed to this final theme – being heard and empowering the patient. Participants described their struggle to have their views and opinions heard by healthcare professionals and their desire to have greater involvement in their own care.

6.4.1 Being heard

Despite having regular medical reviews, participants frequently did not feel that their opinions were being heard and taken seriously by the doctors managing their care and this significantly affected their care experience:

> *I used to feel that, that what I was saying to them they wouldn't believe me, I used to think that, that they think I was making it up.....and I think they used to think half of its in my head* ('Sunita' Interview 7, page 5, lines 19-21)

Participants' reported experiencing considerable anxiety at times, for example when having CVCs inserted in theatre several requested sedation, but often healthcare professionals dismissed their concerns without explanation:

> *It was horrible, the whole experience was horrible, because I wanted to be sedated and be asleep and they were like no, we can't do it like that* ('Sunita' Interview 7, page 12, lines 18-19)

Medical ward rounds, as described by the participants, were characterised by large groups of healthcare professionals visiting patients. Participants reported that this was a barrier to them being able to voice their views and opinions, as Rebecca explained:

> *It's not, conducive to..... a personal conversation it, it's very much a kind of ..... factual interchange really.....and I know some people will*

> *probably not have any problem just chatting away and, and kind of, getting on with it but I, I can't, I find it quite intense, just because.....you don't know who you are talking to, or you are talking to one person but then you've got lots of ears and eyes* ('Rebecca' Interview 4, page 13, lines 21-26)

The participants' comments suggested that they wished to have their views heard and to be involved in decisions about their nutritional care. The approach to deciding to start PN, as described by the participants, did not in most cases reflect a patient centred model of care. The participants were frequently informed that PN was the only option and were not apprised of the risks associated with the treatment or any potentially alternative options. This failure, on the part of the health professionals, to discuss the rationale for starting PN resulted in considerable anxiety:

> *It made me feel very angry and very out of control, vulnerable, because, because I didn't understand why* ('Steven' Interview 3, page 20, lines 2-3)

The care reported by participants requiring PN in this study largely reflected the 'biomedical model' of care[31]. A biomedical approach can be appropriate in some care settings e.g. critical care, emergency care, where urgent and complex decisions are required. However these were not the settings that the participants of this study described. Decisions were being made by health care professionals without the involvement of the patient and without provision of sufficient explanation and information. This was reflected in the reports where CVC insertion was arranged without the participant being aware of the risks or benefits of the treatment being arranged or of any potential alternative. The failure to listen to patient views or concerns indicates that health care professionals do not operate in a patient oriented manner. A recent joint report into nutritional care by BAPEN and PINNT (Elia and

[31] The 'biomedical model' focuses on the reduction of patient illness to a set of symptoms which are investigated, using a problem solving approach, in order to identify and treat the underlying disease process (Mead and Bower 2000)

Wheatley 2014) had similar findings. Questionnaires, followed by round table discussions were conducted with nine patient organisations and two NHS Trusts to explore: 1) whether adequate priority had been given to nutrition and hydration services and whether they have improved, 2) whether patient experience of nutrition support had improved and 3) whether inequities in nutritional care had been adequately addressed. The report indicated that patients and carers felt little progress has been made in delivering patient-centred nutritional care. They found that patients were not involved and included in their nutritional care in a meaningful way and the authors call for action to change the culture in NHS organisations to improve nutritional care.

A patient centred model of care is now advocated within healthcare (Picker Institute 2012), which is congruent with what the participants suggested would be preferable. A review of the related literature shows that patient centred care is difficult to define and it has been conceptualised by different professional groups in a variety of different ways with failure to have a commonly agreed definition. The Picker Institute (2012) describes eight principles of patient centred care (see Appendix 1), which has informed numerous surveys of patient experience in healthcare e.g. NHS Adult Inpatient Survey (Care Quality Commission 2015). A patient derived definition is that of the *International Alliance of Patients' Organizations (IAPO)* which states that "the essence of patient-centred healthcare is that patients are at the centre of the healthcare system and therefore that the system is designed around them" (IAPO 2007: p12). Different groups emphasise different aspects of patient centred care and this results in difficulty applying this model of care in practice. In an attempt to try and address this, Kitson et al. (2013) conducted a narrative review of sixty articles to identify the common core elements of patient-

centred care. They found few common definitions of the concept of 'patient-centred care' but were able to identify three core themes:

1) *Patient participation and involvement.* The patient participates in their care as a respected and autonomous individual. The care provided is individualised based on both the physical and emotional needs of the patient.

2) *Relationship between the patient and the health professional*. This theme included:

- Having a genuine mutually respectful clinician-patient relationship,
- Open communication of knowledge and expertise between the patient and the professional
- The health professional having the appropriate skills and knowledge to support patient decision making
- Having a cohesive and cooperative team of professionals focused on patient goals

3) *The context where care is delivered*. This theme refers to the lack of a common definition and different conceptualisations of patient centred care in the literature and by different professions. This results in difficulties translating theory into policy to enable positive changes to patient care in practice.

The strength of this review is its attempt to consolidate literature from across numerous disciplines. However synthesising evidence from such a large number of studies (n=60) results in only broad descriptions of the themes which does not enable patient centred care to be defined in detail. The findings of this study, when viewed through the lens of Kitson et al's (2013) three themes, appear to suggest that a patient centred model of care has not been adopted by the healthcare professionals caring for patients requiring PN. The theme of p*atient participation and*

involvement was not reflected in the participants' accounts in this study. The decisions they did make in partnership with the nutrition support team were often overturned by other members of staff, and the participants did express desire for greater involvement in their care. The second theme of establishing a genuine *relationship between the patient and with healthcare staff* was also not consistently evident in the participants' descriptions of their experience. This was particularly apparent in relation to communication about PN as a treatment option, the commencement of oral diet, and the lack of cohesiveness and cooperation of healthcare professionals. Being heard, acknowledging and respecting the patient voice is a crucial part of these two themes and links to the findings of this study. The third theme - *the context where care is delivered* - relates to healthcare policy and organisational structure – and was not explored specifically in this study. Mead and Bower (2000) contributed significantly to an understanding of the core conceptual dimensions of patient centred care from a medical perspective. These dimensions are:

1) *The biopsychosocial perspective*. Adopting this perspective broadens how illness is portrayed by taking into consideration the biological, psychological and social factors that often interlink e.g. by addressing the health concerns of an elderly man who is depressed and malnourished who is unable to cook for himself following the death of his wife, through nutritional advice, bereavement counselling and offering home delivery of pre-prepared hot meals.

2) *The patient-as-person*. This dimension focuses on gaining an in-depth understanding of the meaning attributed to illness by individual patients and their expectations, fears and feelings.

3) *Sharing power and responsibility*. This dimension moves away from the traditional paternalistic relationship between physicians and patients and advocates for "the legitimacy of lay knowledge and experience" (p1089). From this perspective patients are no longer considered passive recipients of care but "active consumers" of health care (p1090).

4) *The therapeutic alliance*. This focuses on the nature of the personal relationship established between doctor and patient which has been shown to influence adherence to treatment.

5) *The "doctor-as-person"*: Focuses on the development of the personal qualities of a doctor and the influence of these on professional practice.

Mead and Bower's (2000) influential conceptualisation of patient centred care links to several issues raised in this study. The *biopsychosocial perspective* and the *patient as person* conceptual dimensions consider other factors that influence the patient experience and reflect the phenomenological concept of the individual lifeworld. Factors and issues that emanate from the person's lifeworld will influence how they manage or cope with the experience of intestinal failure and treatment, and the impact of a changed body-image. Similarly, the meaning individuals attribute to food and how they cope with dietary modifications within the context of their own lives. Patient centred care can be promoted by listening to the patients, by understanding and supporting patients in adapting to these changes and by tailoring the care provided by taking into account their lifeworld experiences. Participants in this study were involved, at times, in shared decision making regarding their nutritional care with members of the NST and these occasions reflected *shared power and responsibility.* In addition, most participants reported that the personal qualities of members of the NST helped to build an effective therapeutic relationship

in keeping with *therapeutic alliance* and '*doctor as person'* dimensions. This suggests that the NST had a more patient centred approach. However, the findings of this study suggest that all the teams involved in the care of patients requiring PN need to adopt a coordinated, patient centred approach in order for patients to feel that their views are important and for their experience to be improved.

The participants in this study all discussed issues related to the competence and knowledge of nurses in relation to CVC care. West, Barron and Reeves (2005) conducted a survey of nurses from twenty acute London hospitals. A postal questionnaire was distributed and 2880 nurses responded (response rate 47%). The authors reported that the majority of nurses identified the quality of care on their ward as good, very good or excellent (91.4%) however, many nurses felt overworked (64%), had inadequate time to perform tasks such as addressing patients' anxieties and concerns (71.6%) and provide patients and relatives with information (59.7%). Systemic barriers to patient centred care included lack of time, staff, and equipment. The authors also observed that, despite their assessment of the quality of care on the wards, the respondents identified deficiencies in safety, the level of patient comfort and privacy, and the information provided to/for patients on the wards. Interestingly, in a subsequent publication based on the study results (Reeves, West and Barron, 2005) nurses who reported more barriers to patient centred care were more likely to state their intention to leave their current employers. Esmaeili, Ali Cheraghi and Salsali (2013) conducted a qualitative study to identify and describe the barriers to patient centred care from the perspective of nurses'. They conducted in-depth semi-structured interviews with twenty-one critical care nurses. Data analysis revealed three core themes:

- *Lack of common understanding of teamwork*. The nurses in the study highlighted that adopting a patient centred approach was a nursing responsibility but that in their experience other professionals tended to pursue their own agenda in making decisions for patients. In addition, they identified that poor coordination between healthcare teams resulted in care that was not patient centred.
- *Individual barriers.* Many of the participants' felt that a love of nursing and acceptance of the profession's philosophy and standards of practice were congruent with the principles of patient centred care. They identified that those who lacked professional interest and motivation and had out of date nursing knowledge could inhibit the provision of patient centred care.
- *Organisational barriers.* An appropriate work environment, with sufficient staff numbers and skill mix were identified as key contributors to providing patient centred care. They felt that a failure to establish this type of practice environment affected the time available to provide patient centred care and created additional workload pressures for staff. A lack of nursing-specific guidelines to inform staff how to implement patient centred care was identified as a barrier. Senior nurses or those in specialised roles that promoted patient centred care and were available to provide support and guidance were reported to be key facilitators in encouraging nurses to adopt a patient centred approach.

Changing practice to enable a more patient centred model is important to the care of patients requiring PN. A number of strategies that would

encourage staff to adopt a patient centred approach have been identified e.g. training of healthcare professionals, providing tailored information for patients, organisational changes to foster better interprofessional communication and coordination of clinical teams. Dwamena et al. (2012) assessed the effects of interventions (education and training of health professionals) aimed at promoting patient centred care. Training interventions were found to be successful in transferring patient centred skills to staff, however the effects on overall patient satisfaction, health behaviour and health status were mixed. Participant reports and studies reviewed suggests that clinical practice is frequently not patient centred as a result of numerous factors including healthcare professionals' not having sufficient time to provide patient centred care, a lack of knowledge and understanding of the benefit to patients and organisational factors that inhibit the effective coordination of services. In addition, 'grey' areas of practice between professionals may result in incorrect or conflicting information being provided to patients and limit their involvement in decision making.

A holistic approach to practice can be difficult due to the specialised nature of medicine. Medical/surgical teams focus their assessment of patients in accordance with their area of speciality e.g. the colorectal surgeon, the NST, the gastroenterologist. These 'experts' or 'specialists' need to support the patient by providing relevant information that is tailored to each individual and accessible in order to promote patient autonomy in the decision making process. This is a particularly salient issue within acute healthcare where patients interact with many different specialities. PN is a medical technology that requires speciality knowledge and skill, however, it is clear that, for the participants in this study, PN had a more

profound effect on their sense of self and their experience of consuming food which is not understood by the clinical team members. Research such as this, that has been rigorously designed and conducted, contributes to addressing this gap in knowledge.

6.4.2 Empowering the patient

Over time participants developed their knowledge and became very informed about PN, as described by one participant:

> *My understanding is that it is, erm, a bag full of nutrients, that's administered through your veins and it goes straight into your bloodstream, so you don't need to use your bowel and your stomach or anything else, so its, it's kind of, a way of being fed without using what doesn't work very well* ('Rebecca' Interview 4, page 7, lines 29-32)

Participants who had experienced a CRBSI had a heightened awareness of the risks associated with this method of feeding and sought information about how the CVC should be managed. The CVC care and the connecting and disconnecting of the PN solution were the responsibility of the nursing staff but, as the participants became more knowledgeable, they felt empowered to question the nurses about their technique and attitude towards the CVC care process:

> *It was the nursing staff at the hospital [who cared for the PN], it, it was really weird because they all had their own ways of doing it and I was always cautious and, really used to look at what they were doing because sometimes they would come..... with erm gloves on, sometimes they wouldn't, sometimes they would flush it, sometimes they wouldn't, and then I'd have to speak to [nutrition nurse] to say, if you tell me properly what's gotta happen and then I used to say to them "you've got to do this, you've got to do this"* ('Sunita' Interview 7, page 18, lines 7-10)

The participants reported that with increased knowledge they were able to assume more responsibility and ownership for the management of the CVC:

> *Yeah, because, it's me that's, its mine, and its, although I was told, you know, it, it I didn't actually take on that responsibility straight away but its, it's yours in the bathroom, it's with you when you go for a shower, it's with you all the time* ('Rebecca' Interview 4, page 11, lines 3-5)

The participants clearly wished to be informed and to understand both their medical condition and the treatments they were receiving and most of them sought information from the internet in order to satisfy their need for information:

> *I looked it up on the internet what TPN was, read all about it, so we knew what it involved* ('Susan' Interview 6, page 8, lines 4-5)

Their comments highlighted that more information, particularly in written form, was desirable in order for them to acquire relevant good quality information to aid their understanding. However, this depended on them taking the initiative and actively seeking the information:

> *They rely to a great extent on you asking the right questions* ('Thomas' Interview 1, page 22, line 5)

Becoming empowered, through acquisition of knowledge, enabled participants to assert which treatment option they preferred:

> *The two teams said different things for the following night.....the nutritionist said..... that I could have it at.....half the rate.....but they wanted to put it on what the doctor had said, not the nutritionalist.....and I went "No", and I just point blank refused to have it set up at the faster [rate] and that night I had it running for the whole night which was what I was supposed to.....but again, I had to fight, I knew something wasn't right and comfortable and I couldn't see why I should be swelling up and being in pain* ('Sarah' Interview 10, page 18, lines 17-26)

Participants in this study made it clear that they wished to be involved in the decision making regarding their treatment, however it appeared that the healthcare professionals involved failed to provide sufficient information for participants to feel able to be informed contributors to discussions regarding their care. It was apparent that when participants acquired the knowledge that they desired they felt empowered to be involved and to make their voices known. Shared decision making and partnership between the patient and the healthcare professionals is a core dimension of patient centred care (Barry and Edgman-Levitan 2012) but this dimension was not evident in the participants' accounts of their experience. A

fundamental component of this dimension involves the setting of patient derived goals. None of the participants in this study reported any discussions with healthcare professionals regarding nutritional goals that they wished to achieve. A coordinated 'seamless' patient centred approach is unlikely to be achieved without goals being agreed upon by the patients and the teams providing care. Patient derived goals encourage healthcare professionals to focus on supporting the patient in achieving their goals and on measuring progress using outcome measures that are meaningful to them. Goal setting and outcome measurement will be discussed further in the recommendations for practice section of the conclusion chapter.

A number of authors have addressed the issues related to patient empowerment and involvement in partnership decision making. The latter is a central component of patient centred care, however negotiating the degree of involvement can be complex. Not all patients wish to engage fully in decision making but would prefer health professionals to direct their care (Lorig 2012). Légaré et al. (2008) updated an earlier systematic review (Gravel, Légaré and Graham 2006) on the barriers and facilitators that influence health professionals' ability to implement shared decision-making in clinical practice. The three most commonly reported barriers were: time constraints, lack of applicability due to patient characteristics and the clinical situation. Interestingly, the authors did not find evidence to suggest that more time is required to engage in shared decision-making, however, the second and third barriers may suggest that health professionals screen patients based on their opinion of patient preference or whether they think patients would benefit from shared decision-making. Such a screening process is largely subjective and may not be accurate. The three most commonly reported facilitators of shared decision-making were: the motivation of health professionals, the perception that putting

shared decision making into practice will improve patient outcomes, and lead to improved healthcare processes.

The study participants clearly indicated that when they obtained sufficient relevant information they felt empowered to take more responsibility for the management of their medical condition and treatment. Examples included one participant taking 'ownership' of her own CVC highlighting the role she assumed in managing her care. Culkin, Gabe and Madden (2009) reported positive changes to oral nutritional intake in patients with intestinal failure who were given individualised nutritional advice by a dietitian in conjunction with a written booklet. Patients receiving home parenteral nutrition (HPN) are often provided with information to facilitate self management of their HPN and CVC care with the aim of enabling them to manage without daily nursing visits and promoting independence. No research studies were found investigating patient self-management of HPN care. However, Møller et al. (2005) conducted a randomised controlled trial investigating CVC self management in patients with haematological malignancies who were undergoing chemotherapy. The intervention group (n=42) received intensive training to enable them to manage their tunnelled CVC in both the inpatient and outpatient settings. The control group (n=40) received standard CVC care provided by nursing staff only. The authors demonstrated a statistically significant reduction in the incidence of catheter related bloodstream infections (CRBSI) ($p=0.02$) in the intervention group. This study highlighted that patients, provided with the relevant information and training, were able to learn the techniques required to manage the CVC and complication rates could be reduced. The authors suggested that the reduction in CRBSI occurrence was achieved partly through teaching patients the strict protocols that should be followed but also through the reduction of risk of poor CVC care due

to inexperienced or poor quality nursing care. Interestingly, approximately one-third of the participants in the control group described direct conflict with health care professionals due to improper CVC management leading to feelings of anxiety, conflict and lack of control. The intervention group experienced greater control and a sense of responsibility for their own care. Most of the participants in both groups consciously tried to hide the CVC as it was perceived as a physical representation of their illness. Møller et al's. (2005) findings reflect this study participants' description of their experiences for example, one participant explained that she did not want 'the PN running when it was visiting time due to it making her look 'sick'. Self - management of CVCs used for PN in acute settings is not likely to be feasible as patients are usually acutely unwell and frequently only require a short duration of PN. However, research, including this study's results, suggests that providing information tailored for each individual can empower patients' to assume responsibility for their own care.

6.4.3 Summary

The participants in this study made it clear that they wished to have their voices and opinions heard by the healthcare professionals caring for them and to be involved in decisions about their treatment. They wanted to receive information that was relevant to them in order to understand the PN and to take a more active role in their own treatment. However, it was apparent from this study that this did not occur routinely and the organisation failed to operate in a patient centred manner. The research literature explored indicates the benefits of adopting a more patient centred approach to care.

6.5 Conclusion

The results from this study and the research reviewed have numerous implications for practice. Recommendations that can contribute to improved practice in both local and wider contexts can be made based on this new information which will be discussed in the next and final chapter.

Chapter 7: Conclusions and Recommendations

7.1 Choice of methodology and methods

A qualitative approach was chosen to guide this study to enable in-depth, detailed data to be obtained and to allow the patient experience to be contextualised, including both positive and negative aspects of care, in order to understand the experience as a whole. Descriptive phenomenology was chosen as the research methodology for several reasons:

- Adopting a specific methodology enhances the coherence of the study design
- Descriptive phenomenology is firmly rooted in the experience of the participant and avoids undue influence of external theory thus staying true to the experience and the participant's 'voice'
- By focusing on the lived experiences of the participants it kept the research focused on practice-based issues

Descriptive phenomenology provided guidance and structure to the study. By understanding and using phenomenological reduction I developed as a researcher, I moved beyond the role of an interested nutrition clinician, to approaching this study with an overwhelming desire to not only hear the participants' stories, but to understand, to be there, in their story, as it was told. Phenomenology has taken me beyond simply asking questions, to wanting to understand the individual, considering the information they provided within the context of their lifeworld experience. The choice of descriptive phenomenology was particularly important, as I wanted the data to remain rooted in the accounts of the participants and the meaning that *they* brought to the experience, rather than interpreted through a specific theoretical lens that, as researcher, I might have brought to the research. Controversy exists over the use of bracketing in phenomenological research with some suggesting that there

is a requirement to completely bracket out the presuppositions and experience of the researcher. However, in this study I took the view, articulated by Giorgi (2012), that the bracketing process can be used to explore, acknowledge and make explicit the researcher's views, and through adoption of the phenomenological attitude i.e. openness to the account of the participant, rich data could be achieved.

7.2 Study limitations

In-depth interviewing was the chosen data collection method, it is a method commonly used in phenomenological research as it focuses on the individual and encourages participants to tell their story fully and in their own words (Carpenter 2010). One or two lengthy interviews are usually conducted in phenomenological research (Carpenter 2010, Finlay 2011, Giorgi 2012), in this study a single interview was conducted with each participant and the length of interview varied considerably. However, it was felt that as much rich in-depth data was achieved during these interviews as was possible, according to the individual abilities of the participant and it was not felt that any further information pertaining to the research question would be achieved with a further interview. Colaizzi (1978) recommends, in the final stage of his phenomenological analysis method, that data is taken back to the participants for review and validation, therefore a further interview could have been conducted at this stage. This was not achieved in this study and there was limited involvement of participants during the data analysis phase. The participants were consulted at the beginning of the analytic process (the basic level of member checking) to ensure the written transcripts represented the interviews that had been conducted, with the aim of enhancing the credibility of the study. However, due to the long data collection

period it was not possible to revisit participants at later stages of the data analysis process.

An appropriate additional data collection method could have been participant diaries, which would enable the journey of the patient to be chronicled throughout the experience of PN rather than the retrospective account achieved from interviewing (Furness and Garrud 2010). Interviewing is limited by the memory of the participant, the questions asked by the researcher and the rapport achieved between the interviewer and participant. Patient diaries would allow the research to get closer to the lived experience, but are labour intensive for the participants. This could be explored in future research (Furness and Garrud 2010).

There were two key limitations in the data collection phase of this study, firstly the failure to record one of the interviews fully – measures were taken to address this immediately, including participant involvement in validating the researcher interview recollections, however some data, and quotations, were inevitably lost due to this mistake. The other limitation was the limited interview conducted with the participant who wished to be interviewed on a ward, with the resultant noise and interruptions. Despite this affecting the interview, it was essential to respect the participant's wishes regarding interview location.

During this research study I continued to work as a senior specialist dietitian for the nutrition support team, the service that the participants accessed. The issue of potential conflict between the clinician and researcher roles added complexity to the study process and could have unduly influenced the results; this was addressed through reflexivity and bracketing. In all qualitative research the relationship between participants, researchers and their wider social world is actively

acknowledged (Finlay 2011). Researchers recognise their central role in a co-construction of data and are required to explore this dynamic reflexively in all rigorous qualitative research (Finlay 2011).

The issue of clinician-researcher role conflict was addressed throughout the study process through reflexivity and bracketing which was supported by lengthy discussions with the research supervision team. These strategies revealed my strong desire to uncover what it was like for participants to receive PN, and to use the study findings to improve the experience, and enabled me to be open to both positive and negative responses from participants. Participants were informed of my clinician role prior to interview and assured that their responses would be confidential – this was particularly important for those participants who required ongoing clinical care by the nutrition support team. I had acquired a thorough knowledge and understanding of PN through my clinical practice and I found that this helped establish rapport with participants. Yanos and Ziedonos (2006) also described this positive influence of prior knowledge. The terminology I used in my communication with participants mirrored that which they used e.g. PN, TPN, feed bags etc. and enhanced our mutual understanding during the interviews. None of the participants appeared to be reluctant about discussing their experiences, and they all spoke very openly and honestly during the interviews.

Yanos and Ziedonis (2006) highlighted the advantages that 'patient-oriented clinician-researchers' offer by facilitating research that is meaningful to practice and which can positively affect clinical services. However, the dual role can also be confusing to participants who may be concerned how the information provided in the research context may influence their clinical care, or who may misunderstand the research interview as being an opportunity to obtain health advice (Colbourne and

Sque 2004). The primary purpose of the qualitative interview is to obtain data to inform the research question (Jack 2008). During the interviews several participants asked questions to clarify issues related to their hospital admission. In order to separate the clinician-researcher roles these issues and questions were acknowledged but not addressed during the interview. After the interview resources were offered to address the issues that had been raised. This was considered to be an appropriate balance between being a researcher and having the clinical knowledge to assist the participants in understanding the experience and treatment they had received. Addressing the questions after the research interview had been completed ensured that the participant responses were not altered (Colbourne and Sque 2004).

The clinician-researcher role also creates a potential power imbalance due to the knowledge and position of the researcher as a nutrition health care professional. However the participant also has power, by being in control of the amount and type of information disclosed to the researcher. The focus for this study was therefore on the co-construction of knowledge, with the unique knowledge and insight of the participants and prior experience and beliefs of the researcher being recognised, through reflexivity and bracketing (Karnieli-Miller, Strier and Pessach 2009). The location of the interviews were chosen by the participant in order to put them at ease - in the majority of cases (n=8) this was the participant's home – and this helped to address any potential power imbalance.

Determining a sample size when planning qualitative research is difficult and as previously discussed there are large variations in what is recommended for a phenomenological study (Creswell 1998, Morse 1994). A larger sample size may have revealed a wider range of experiences, but may not necessarily have altered

the overall findings. It is also important to remember that a qualitative approach to research focuses on depth and understanding, rather than breadth of sample size (Liamputtong 2010, Todres 2005). The sample size was determined by a combination of availability of participants, depth of information shared at interview and pragmatic considerations regarding length of time spent on data collection. The sample size of ten was considered to provide sufficient new, in-depth information to inform the aim of the study. After ten interviews no new information was arising and significant new insights about the experience of PN had been achieved.

7.3 Fundamental structure of the patient experience of receiving parenteral nutrition in an acute care setting

Parenteral nutrition involves the provision of nutrients via a central venous catheter directly into the bloodstream. It is required due to the presence of intestinal failure which results in the inability of the body to absorb nutrients via the gastrointestinal tract. The provision of PN is lifesaving and associated with improvements in self identity and illness perception due the improved nutritional intake. The altered function of the gastrointestinal tract results in a significant change to the embodied experience of eating and there is a loss of control over decisions related to food intake in acute care. Complications related to PN e.g. catheter related bloodstream infections or catheter occlusion, disrupt the provision of nutrients and cause anxiety to the patient. This study has highlighted that in this NHS hospital, the organisation of care for patients requiring PN lacks coordination. It is also frequently hindered by healthcare professionals without nutritional expertise providing advice that conflicts with that given by the NST. A hierarchical structure exists within the acute healthcare provided at this Trust that appears to devalue the advice provided by

healthcare staff with nutritional expertise. NSTs have greater credibility with the patients due to their knowledge and expertise and because they work in a more patient focused manner, however their role is diminished by the structure of the overall healthcare services.

7.4 Implications for practice

The main findings of this study focus on the central role of eating for patients requiring PN in acute care. The impact of the physical changes due to intestinal failure coupled with the environment and barriers relating to food provision in hospital have not previously been explored in this patient group. These findings indicate that in order to maximise oral intake to enable the cessation of PN or to promote intestinal functioning a number of inhibiting factors need to be addressed, these include:

- Participants being required to order food from the menu a day prior to consumption, which caused numerous difficulties when dietary restrictions/allowances were frequently changed
- The environment of the ward, which was described by participants as not being conducive to eating due to the presence of unwell patients who were experiencing unpleasant symptoms such as vomiting, pain
- The poor quality and unsuitable temperature of the food provided
- Patients not being clear on what oral nutrition they were supposed to be consuming due to inconsistent information from healthcare professionals and poor communication with catering staff

Insight has been provided into the complexities of the interprofessional working practices that exist within this acute healthcare trust, which fails to provide patient centred care. This was found to affect both the experience of the patient and the trust in the care being provided. This is unlikely to be unique to patients requiring PN in this trust and may reflect the organisation of acute healthcare services. Despite the national recommendation that all acute healthcare trusts should have a NST (NICE 2006) this study has shown that, in this hospital, such teams can be limited in their effectiveness due to poor communication and coordination with the medical/surgical teams leading patient care. This finding was most pronounced when enteral (oral or tube) feeding was being initiated into the gastrointestinal tract. Furthermore, the distribution of patients with intestinal failure on multiple wards across the hospital site with numerous different medical / surgical teams leading their care hinders the ability for these patients to have a consistent approach to their nutritional management.

The study findings highlighted the participants' desire for greater involvement in decision making and empowerment that is not are not consistently being integrated into clinical practice. Insufficient information is being provided in practice to enable informed decision making by the patient. This is particularly evident in relation to PN as a treatment, the alternative treatment options available and how, and when, enteral feeding (oral, or via tube into the gastrointestinal tract) is introduced.

Numerous issues were raised in the study associated with the quality of CVC care provided by ward nursing staff. Participants reported that some staff had insufficient knowledge and skills in PN resulting in mistakes and poor practice. In some cases this resulted in patients acquiring avoidable catheter related bloodstream infections. The consequences of best practice not being available

included the temporary cessation of PN whilst the infection was treated, additional procedures to remove and reinsert CVCs, and patient distress. Delivery of best practice is essential for patient safety and professional standards. Nurses are required by the Nursing and Midwifery Council to follow a code of professional practice (Nursing and Midwifery Council 2015) to ensure competence to practice nursing safely. Nurses should therefore not be carrying out tasks where they do not have the necessary skills and training. This is a major patient safety issue that requires immediate action.

The aim of the study has been achieved in that new knowledge has been generated about the patient experience of PN in acute care. The existing body of knowledge related to patient experiences of HPN which has been developed to offer a new perspective on how patients in another environment, acute care, experience PN. The acute care setting is complex, with multifaceted issues affecting the experience of the patients. The findings of qualitative research are specific to the study setting and individuals involved and it is therefore not possible to demonstrate that these results are applicable to other acute hospital PN services (Shenton 2004). However, to promote transferability, information has been provided to enable other hospitals to compare the reported experiences in this study with that of their own patient group and organisational structure. This study focused on the experiences of ten participants, from a single research site in the UK, who were interviewed at a single point of time regarding their experiences of receiving PN at an acute teaching hospital. The participants received PN on numerous wards (including oncology, gastroenterology and general surgery) and numerous medical / surgical teams were involved in their care. Further information on the participant profile was provided in Appendix 4. All the participants had involvement with the NST as is required in the

study hospital. It will remain up to the reader to consider the information presented and determine the degree of transferability of the results to their own context.

7.5 Recommendations for practice

The following recommendations have been developed as a result of conducting this study and disseminating and discussing the findings with relevant professional groups:

- Patients should be provided with clear verbal and written information about PN as a treatment, including benefits, risks and potential alternatives and be involved in the decision to commence treatment.
- Where oral diet or enteral tube feeding is being used concurrently with PN, clear information should be provided to patients regarding recommendations, including rationale, and possible alternative courses of treatment. Nutritional goals should be mutually agreed. Where possible nutritional advice should come from an allocated person or person(s) with the necessary expertise e.g. NST or dietitian. Written information should be provided for the patient and changes to dietary restrictions communicated between the healthcare team and the hospital catering service.
- The process of food ordering for patients with intestinal failure should be reviewed.
- A pleasant area for eating meals is required for patients on wards. Day rooms should be utilised, where available, and wards should be prepared prior to meals to remove unpleasant items e.g. vomit bowls.

- Regular robust audit needs to be conducted to assess catheter related bloodstream infection rates and comprehensive training needs to be available for all nurses caring for patients requiring PN.
- The food provided to patients with intestinal failure should be audited, including whether the correct meal was ordered for the mutually agreed dietary requirement, whether this was received, and the temperature and quality of the meal.
- A method of more effective communication of oral dietary requirements needs to be discussed between nutrition professionals, nursing staff and catering staff to ensure the diets agreed with patients are actually ordered and delivered.
- Interventions to promote the patient centred model of healthcare should be implemented including:
    - Training for healthcare workers looking after patients requiring PN on how to promote patient centred care.
    - Providing individually tailored information to patients, that is relevant and meaningful to them, to enable them to understand their condition and how it is being treated and facilitate their active involvement in managing their own health care.
    - Offer individually tailored information about the management of CVCs to patients in order to empower them to be involved in PN CVC care and to constructively question the standards of care they receive.
    - Consider the allocation of a nutrition key worker for patients requiring PN. This will provide a single key point of contact for the patient for support and for the provision of consistent, tailored information, according to the individual needs and wishes of the patient.

- NSTs should actively develop working relationships with the medical / surgical teams managing individual patients requiring PN and negotiate role boundaries and pathways for communication to improve coordination of nutritional care.
- Patients requiring PN should be located in a single ward area where medical / surgical / nutritional treatments can be better coordinated and targeted training can be provided for healthcare professionals.

7.6 How the findings of this study have been used or plan to be used to change practice

Dissemination of the study findings has commenced with abstracts and posters accepted and presented at both local and national conferences (see Appendices 23-26). A journal article will also be written and submitted to a peer reviewed journal. At the study site, the findings were presented to the nutrition support team and a workshop on ways the team could improve the patient experience was facilitated by the researcher. The team has had lots of new ideas about how the patients' experiences can be improved and how working practices can be changed as a result of new knowledge and understanding generated by this study. I have initiated discussions with the Trust medical consultant who leads on patient experience with the aim of improving communication and working relationships between the surgical and nutrition support teams.

Enhanced training of staff on the care of CVCs was implemented prior to study completion by the Trust nutrition nurses due to the unacceptably high levels of catheter related bloodstream infections identified from local audit by the nutrition support team. Subsequent regular audit has shown a large reduction in this complication. This study highlighted the role the patient can assume in their care

and the importance of providing individually tailored information on CVC management to support and empower the patient in that role. These aspects of patient-centred care were presented at a recent workshop and are being discussed by the nutrition support team.

Dietetic assistants are being utilised by the nutrition support team to facilitate individualised menu ordering and provision of extra items from the kitchens to support the delivery of restrictive diets in intestinal failure patients. In addition an electronic meal ordering system is being considered across the hospital and is currently being explored.

7.7 Areas for future research

Based on the results of this study, a number of areas that would benefit from further investigation have become apparent. The development and assessment of strategies to better coordinate the nutritional care of complex intestinal failure patients is an important area to explore. This could take the form of organisational changes e.g. joint surgical and nutrition ward rounds, or through education of other teams about the role of the nutrition support team and the impact that poor nutritional advice has on the patient experience. Any interventions introduced to improve patient centred care for those requiring PN will need rigorous evaluation to assess the effectiveness and benefit to patients. This could take the form of patient and/or staff focus groups, patient interviews and the use of selected, relevant, reliable and valid outcome measures. Validated tools already exist in other settings, for example, the 'Client Centred Rehabilitation Questionnaire' (Cott et al. 2006) which could be adapted for use with this patient group.

A survey to assess the knowledge and skills of surgical teams on the nutritional management of intestinal failure patients would be useful to investigate as there is currently little evidence to support the assertion that surgical teams have inadequate knowledge. What evidence does exist considers nutrition support broadly rather than focusing specifically on intestinal failure. This could be conducted through the design of a questionnaire.

Participants highlighted a desire for further information about their nutritional care. This is important in order to support a patient centred approach to care. However, how to best deliver this would need evaluation. This could be done by agreeing desired levels of knowledge with the patient and then evaluating whether this has been achieved through the use of a questionnaire to assess knowledge. Real time data could be gathered from patients with intestinal failure on wards by using patient diaries to enable continuous assessment and improvement strategies to be implemented for patient experience. This is however rather labour intensive for patients especially if they require PN for a long duration.

Strategies to enhance psychological support for patients unable to eat 'normally' due to intestinal failure could take the form of specialised psychological therapies by a psychologist, or by providing training for NST members in how to support patients more adequately.

It was identified that parenteral nutrition may have an influence on appetite regulation and gut hormones in acute care. Investigating the impact that PN has on appetite would enable healthcare professionals to better understand how to facilitate the introduction of enteral nutrition. This would require a controlled clinical trial where patients were given differing amounts of parenteral nutrition solution at the

point when oral nutrition was commenced. The difference in nutritional intake, appetite and gastrointestinal peptide concentrations could then be measured and compared between the two groups.

Parenteral nutrition remains an essential treatment option for the management of patients with intestinal failure however improvements could be made to improve the experience of patients. In conclusion, the experience of PN can perhaps be best summarised by one of the participant's comments:

> *Having the PN, the nutrition, has helped close my hole, helped build my energy levels back up, helped me be able to walk and do things again. I don't think I would still be here if I hadn't been given it [PN] so its got to be a positive, it saved my life* ('Sunita', Interview 7, page 28, lines 19-22)

APPENDIX 1: Picker Principles for Patient-Centred Care (Picker Institute 2012)

The 8 Picker Principles of Patient-Centred Care

- Respect for patients values, preferences and expressed needs
- Coordination and integration of care
- Information, communication and education
- Physical comfort
- Emotional support and alleviation of fear and anxiety
- Involvement of family and friends
- Continuity and transition
- Access to care

APPENDIX 2: NICE Quality Statements for Patient Experience (NICE 2012b)

Quality Statement	Description
Quality Standard 1	Patients are treated with dignity, kindness, compassion, courtesy, respect, understanding and honesty
Quality Standard 2	Patients experience effective interactions with staff who have demonstrated competency in relevant communication skills
Quality Standard 3	Patients are introduced to all healthcare professionals involved in their care and made aware of the roles and responsibilities of the members of the healthcare team
Quality Standard 4	Patients have opportunities to discuss their health beliefs, concerns and preferences to inform their individualised care
Quality Standard 5	Patients are supported by healthcare professionals to understand relevant treatment options, including benefits, risks and potential consequences
Quality Standard 6	Patients are actively involved in shared decision making and supported by healthcare professionals to make fully informed choices about investigations, treatment and care that reflect what is important to them
Quality Standard 7	Patients are made aware that they have the right to choose, accept or decline treatment and their decisions are respected and supported
Quality Statement 8	Patients are made aware that they can ask for a second opinion
Quality statement 9	Patients experience care that is tailored to their needs and personal preferences, taking into account their circumstances, their ability to access services and their coexisting conditions
Quality statement 10	Patients have their physical and psychological needs regularly assessed and addressed, including nutrition, hydration, pain relief, personal hygiene and anxiety
Quality statement 11	Patients experience continuity of care delivered, whenever possible, by the same healthcare professional or team throughout a single episode of care
Quality statement 12	Patients experience coordinated care with clear and accurate information exchange between relevant health and social care professionals
Quality statement 13	Patient's preferences for sharing information with their partner, family members and /or carers are established, respected and reviewed throughout their care.
Quality statement 14	Patients are made aware of who to contact, how to contact them and when to make contact about their ongoing health care needs

APPENDIX 3: Summary of Patient Experience Literature

Author / Country	Aims of Study	Methodology	Research design	Main Findings	Strengths / Limitations
Baxter (2015) [unpublished] International	To assess the QOL of patients receiving HPN for chronic intestinal failure using the HPN-QOL in a large scale population study	Survey	Cross sectional study 699 Adult HPN patients 14 countries HPN-QOL validated questionnaire self administered or interview guided	Majority of patients report moderate/good QOL Functional scales improved with time on HPN Symptom scales reduced over time as patients adapt Variation in QOL according to underlying illness	**Strengths:** First international study exploring QOL in HPN patients. Used a validated disease specific measurement tool **Limitations:** Unpublished work. Lacking details regarding study design
Chambers, Hennessy and Powell-Tuck (2006) United Kingdom	Define and quantify longitudinal changes in QOL at time of first discharge and over the first year and comparison of telemedicine	RCT Longitudinal	30 participants Randomised to have either telemedicine (video calling) or telephone calls for follow up. SF36, EQ5D, HAD questionnaires used to measure QOL at point of discharge and a set intervals over first year	Telemedicine had no significant impact on QOL. Aspects of QOL improved over the first 6 months in both groups. Opiates and a chronic diagnosis had a negative impact on QOL	**Strengths:** Validated tool used. Real time measures **Limitations:** High attrition rate therefore unable to complete data collection at 1 year. Data collection tool not disease specific. Lack of homogeneity between groups

Dreesen et al. (2014a) Belgium	To identify quality indicators through patients' perspectives of HPN	Qualitative	In-depth face to face semi-structured interviews with 12 patients recently started on HPN (median 59 days), six patients with benign disease, six patients with malignant disease. Purposive sampling Data coded focused on clinical indicators for quality of care	Two structure, 31 processes and 9 outcome indicators identified. Majority of processes related to home care nurse	**Strengths:** Patient perspective on their care. Independent interviewer. Pilot study with 3 HPN patients **Limitations:** Lacking methodological underpinning. Results not presented clearly. Lacking researcher reflexivity. Quality indicators relating to patients relatively new to HPN (<180days)
Dreesen et al. (2014b)	To identify the top three most important outcome indicators according to HPN patients	Survey	Questionnaire developed based on previously identified outcome measures (Dreesen et al 2014a). Nine HPN centres from eight countries participated, recruiting 300 participants (71% response rate)	Catheter related bloodstream infection, survival and quality of life the most important outcome indicators according to this survey however considerable differences between participating centres and duration of patient HPN experience	**Strengths:** 71% response rate, trying to achieve patient involvement in determining significant outcome measures for HPN care **Limitations:** The outcome indicators that participants were asked to rate were derived from a mixture of benign and malignant HPN patients who were relatively 'new' to HPN (<180 days) (Dreesen et al. 2014a) and in this study applied to HPN with benign disease only with a mixture of HPN durations which

					may limit applicability of these outcome measures to their care. It may not be possible to simplify the complexities of HPN care to three outcome measures which would explain the disagreement between participating centres. HPN services will also vary considerably between centres internationally
Elphick et al. (2009) United Kingdom	To determine if there are minor, but common complications of HPN that cause patient distress	Poorly defined – structured interviews and review of medical notes	45 participants from 4 HPN centres. Interviewed and asked the open question “do you get any side effects in relation to your HPN?” these were then explored. Then the direct question “do you have significant problems with muscle cramps?” Data collected on HPN composition, frequency & volume and blood results and medications Frequency of muscle cramps was compared to a control group of IBD patients	Muscle cramps the most common minor side effect occurring in 27% of HPN patients and occurred in a greater proportion of HPN patients compared to the IBD control group No difference in blood results or feed composition was noted. 9/12 patients who experienced cramps required pharmacological intervention and in 2 cases the feed was slowed	**Strengths**: Unexplored area of complications relating to HPN **Limitations**: Methodological approach not determined. Data analysis process not described. The direct question asking if muscle cramps are a problem is leading - no other minor symptom is asked about directly. Unable to determine if the result is due to prevalence of muscle cramps or due to the approach to the research
El Turabi et	To analyse	Secondary	Analysis examined how	Younger patients	**Strengths:** Large sample,

al. (2013) United Kingdom	data from the 2010 National Cancer Survey to explore variation in reported experience of involvement in cancer treatment decision making	analysis of survey data	involvement in treatment decision varied between 38 primary cancers using logistic regression. Unadjusted odds ratios calculated between patients of different socio-demographic and tumour characteristics and adjusted for age, gender, ethnicity, deprivation, cancer type and hospital	reported substantially less positive experiences of involvement in decision making as did ethnic minorities. Patients with ovarian, myeloma, bladder and rectal cancers reported substantially worse experiences compared to other cancer types	further data on differences between groups **Limitations:** Unable to establish reasons for differences between groups.
Huisman-De Waal et al. (2006) Netherlands	To gain insight into the problems experienced by HPN patients	Survey	Structured interviews 48 participants Content analysis to ascertain central notions. Frequencies of the central notions counted to give percentages of respondents who mentioned each central notion	7 central problems identified: negative emotions, physical problems, social limitations, dependence on others, incapability, complications and patient–care provider problems	**Strengths:** Clear rationale. High participation rate 76% of eligible patients from the two hospitals in the research study; represented approx. two thirds of the HPN population in the Netherlands. Detail provided on methods to improve validity and reliability of the data. **Limitations:** Focused on problems rather than overall experiences. Number of problems participants allowed to report was limited to three. Lacking theoretical

					underpinning.
Huisman-De Waal et al. (2011a) Netherlands	To describe the prevalence and course of fatigue and to evaluate baseline fatigue and the psychosocial and physiological factors in the prediction of fatigue in HPN patients	Survey	106 participants Postal questionnaire completed at baseline and 12 months later. Biochemistry results obtained from medical records Data analysed using descriptive statistics, correlations and linear regression analysis	65% of patients severely fatigued, with 80% experiencing persistent fatigue. No significant correlations between fatigue and biochemical results were found. Baseline fatigue was the strongest predictor of fatigue at follow up. Functional impairment, self efficacy and depression strongly related to fatigue.	**Strengths:** good response rate (71%). Clear detail on data analysis approach **Limitations:** focus on problems, amalgamated sections from numerous existing validated questionnaires but no attempt to pilot new tool / test its validity in a new population
Huisman-De Waal et al. (2011b) Netherlands	Present an overview of vascular access device-related complications in patients on long-term HPN and to assess whether these adversities are related to experienced psychosocial problems and QOL	Survey	Medical notes of 110 patients reviewed for incidence of vascular access device-related complications. Postal questionnaire then sent. 75 patients participated	76% of patients experienced one or more episodes of catheter related bloodstream infection Patients who experienced HPN related complications e.g. central venous catheter infection or occlusion had a higher occurrence of psychosocial complaints	**Strengths:** Good response rate (68%). Detail provided on the questionnaire used **Limitations**: An association is reported and not a causal relationship. Focus on problems rather than whole experience. The authors amalgamated sections from numerous existing validated questionnaires but no attempt to pilot the new tool / test its validity in a new population

Huisman-de Waal et al. (2011c) Netherlands	Describe the quality, quantity and content of care given to HPN patients	Survey	64 participants completed postal questionnaires assessing their satisfaction with contact with healthcare professionals Medical file analysis for demographic/HPN info and to capture 'contact moments' Semi structured interviews with 4 nutrition nurses Semi structured telephone interviews with 13 homecare nurses	Patients reported a focus on the physical and medical problems with little attention being given to psychosocial issues	**Strengths:** Good response rate to patient questionnaire **Limitations:** Unvalidated data collection tool, missing data in patient files, other professionals involved not included
Naithani et al. (2005) United Kingdom	Explored patients' experience with accessing hospital food	Qualitative	Non-participant observation Semi structured interviews with 48 participants Thematic analysis	New information on the factors that impacted the patients' experience of mealtimes including organisational barriers and the key theme that patient's frequently felt hungry. Highlighted that patients' can be satisfied overall with an experience but when explored in more depth important factors can	**Strengths**: Appropriate data collection methods and analytical approach. Observations explored in more depth at interview - triangulation **Limitations**: Sampling strategy and size not discussed. Explanations of approach to methodological rigour and reflexivity lacking. Focus on the *problems* experienced,

				be identified	not the whole experience. Experiences of patients who were too unwell (either physically or due to cognitive deficit) to give consent not captured
Orrevall, Tishelman and Permert (2005) Sweden	To investigate the experiences of HPN from the perspective of advanced cancer patients and their family members	Qualitative	Face to face semi-structured interviews – 13 patients, 11 family members. Nutritional status assessed using the patient completed subjective global assessment, demographic information obtained from medical notes Qualitative data analysed using constant comparison method	Positive feature of HPN was sense of relief & security that nutritional needs were being met. Benefits were said to outweigh the negative aspects. Three main themes: effects of HPN on food intake and mealtimes; autonomy and dependency in relation to HPN; and HPN as a nutritional support salient. Authors highlighted the limitations of the PG-SGA in light of the in-depth information obtained from interview	**Strengths**: Considered positive and negative aspects of the experience. Appropriate method and data analysis approach. Clearly defined patient group. **Limitations:** Lacking description of methodology. HPN use in cancer patients is different in Sweden compared to UK. It can be used in preference to EN in some cases rather than requiring an IF diagnosis, so patient characteristics / symptoms and therefore experiences likely to be different to the UK
Oz, Theilla and Singer (2008) Israel	Assess the quality of life and eating behaviour of patients receiving HPN	Survey	Questionnaire completed over telephone with 50 participants Statistical analysis presented as mean or median and correlations calculated using	Physical activity highly related to emotional and social status. Emotional status influenced oral intake. Oral intake strongly altered. Recommend	**Strengths:** Captures high number of HPN population in Israel **Limitations:** Sample size included 28% children aged 0-5, no adjustment made to data collection

			Pearson's correlation test	that patients be encouraged to increase physical activity levels in order to improve other parameters	tool. Authors suggest a causal relationship between domains which was not proven. Numerous spelling and referencing errors in publication
Persoon et al. (2005) Netherlands	To gain insight into problems experienced by adult patients who were dependent on long term HPN	Survey	Postal questionnaire & structured interviews NB the structured interview part of the study was described in detail in Huisman De Waal (2010) detailed above.	QOL correlated with fatigue, sleeping disorders, anxiety, depression and social impairment ($p<0.02$). Psychosocial problems was the main complaint related to HPN dependence	**Strengths:** High response rate (76%) represents a high proportion of Dutch HPN population. Focus group pilot used to determine topics to include on questionnaire **Limitations:** Focus on negative aspects, did not explore positive aspects of HPN
Saunders, Abel and Lyratzopoulos (2014) United Kingdom	To explore why patients with cancer treated by London hospitals reported worse experiences of care compared to those treated in other English regions	Secondary analysis of Survey Data	Mixed effects logistics regression used to explore whether poorer scores in London hospitals could be explored by patient case-mix (age, gender, ethnicity, cancer type)	Evidence of poorer patient experience in London compared to the rest of England by a median of 3.7%. Despite case mix adjustment still evidence of worse experience.	**Strengths:** Large sample size, representative of cancer patients. Seeking to explore confounding factors **Limitations:** Unable to ascertain the reasons for the differing experiences of patients in London
Schliefert and Carey (2014) Australia	To assess the nutritional status and QOL in a cohort of	Survey	8 participants Nutritional status assessed using subjective global	QOL scores on SF36 lower than Australian norms based on age and gender mainly	**Strengths:** Validated tools with HPN-QOL also being disease specific **Limitations:** small sample

	patients receiving HPN		assessment (SGA) QOL assessed using SF36 questionnaire and HPN-QOL questionnaire	secondary to differences in physical health Patients adequately nourished on SGA Higher grip strength associated with higher QOL	size. Comparison to Australian norms of questionable value
Tsang and Carey (2015) Australia	To explore the impact of HPN on daily living	Qualitative	8 HPN patients Semi structured interviews either face to face (n=6) or by telephone (n=2) Researcher transcribed the interviews Thematic analysis Two researchers coded the transcripts	HPN improved QOL despite social limitations. Majority of patients able to consume food albeit in smaller amounts	**Strengths:** Well described method, second independent coder, sample justified as included all HPN under the care of the hospital **Weakness**: No discussion of researcher reflexivity, not underpinned by a specific qualitative methodology
Winkler et al. (2010a) United States of America	To achieve a deeper understanding of the experience of adults living with home parenteral nutrition	Qualitative	24 participants, purposively sampled Telephone interviews, using template of open questions. Content and Interpretative Phenomenological analysis (IPA).	Participants described QOL as “good” to “wonderful”. Lifestyle affected by health, abdominal pain, stamina, diarrhoea, presence of an ostomy and flexibility in PN infusion times	**Strengths:** Comprehensive description of research design, methods and results. Sampling strategy defined. The concept of data saturation discussed. Strategies for increased methodological rigour described. Depth and richness of information on patient experiences of HPN. Considered positive

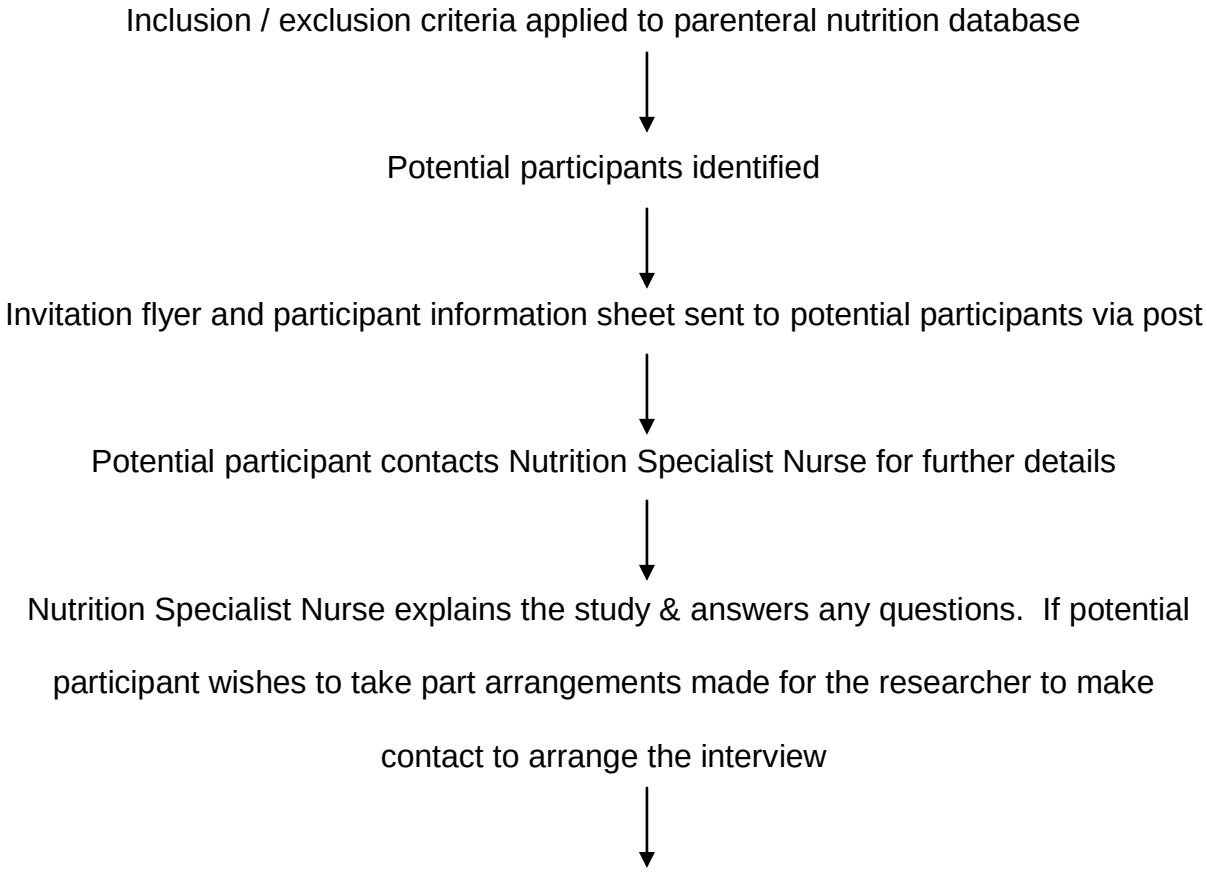
					and negative aspects of experience. **Limitations:** Lacking explanation of researcher reflexivity. No face to face contact with participants
Winkler et al. (2010b) United States of America	To obtain a deeper understanding of how issues related to food and eating influence quality of life	Qualitative	As above to Winkler et al. (2010a)	Three patterns of eating emerged – 1) Eating for survival, 2) Eating for health benefits, 3) Eating for socialisation. Being able to eat and enjoy food is an important aspect of self reported QOL	**Strengths**: This further analysis of the food and eating aspect of HPN patients lives enables further depth of understanding to be added to the information already published in Winkler 2010a **Limitations**: As above, no explanation of researcher reflexivity, no face to face contact with participants
Ziebland, Evans and Toynbee (2011) United Kingdom	Explore experiences of lymphoma care	Qualitative	Semi structured in-depth interviews 41 purposively sampled people Thematic analysis Constant comparison, axial coding and narrative analytical methods	The “surprising” concept of people having positive experiences of lymphoma care. Positive experiences conceptualised as being due to their “good fortune” rather than representing a high quality service that could be expected	**Strengths**: Clear description of methods used for data collection and analysis. Sampling strategy defined. Additional consideration of how participants framed the experience. Researcher had no links to the NHS **Limitations**: Study not underpinned by a specific methodology

APPENDIX 4: Participant Profile

	Gender	Age	Reason for PN (NICE 2006)	No. Days on PN	Type of line	Diagnosis	Ward Type
Participant 1	Male	74	Inaccessible GIT[32]	17	Multi lumen un-tunnelled CVC[33]	Head and neck cancer – severe mucositis	Oncology
Participant 2	Male	65	Non-functional GIT (Obstruction)	27	Multi lumen un-tunnelled CVC	Colorectal cancer causing bowel obstruction	Surgery
Participant 3	Male	67	Non-functional GIT (Ileus)	14	Multi lumen un-tunnelled CVC	Pancreatitis resulting in ileus	Surgery
Participant 4	Female	29	Non functional GIT (Malabsorption)	46	Tunnelled single lumen CVC	Endometriosis affecting small bowel resulting in massive resection & short bowel syndrome	Surgery
Participant 5	Male	66	Non-functional GIT (obstruction)	76	Tunnelled single lumen CVC	Lymphoma causing gastric outlet obstruction	Gastroenterology
Participant 6	Male	78	Non-functional GIT (obstruction)	27	Multi lumen un-tunnelled CVC and Single lumen tunnelled CVC	Diverticular disease – subsequent adhesional obstruction	Surgery
Participant 7	Female	32	Perforated GIT	94	Tunnelled single lumen CVC	Persistent gastric perforation following bariatric surgery (sleeve gastrectomy)	Gastroenterology
Participant 8	Male	63	Perforated GIT (Fistula)	63	Tunnelled single lumen CVC	Enterocutaneous fistula following small bowel resection due to Ischaemia	Surgery
Participant 9	Female	59	Non-functional GIT (Malabsorption)	17	Tunnelled single lumen CVC	Crohns disease – multiple bowel resections resulting in short bowel syndrome	Gastroenterology
Participant 10	Female	45	Non-functional GIT (Ileus)	18	Tunnelled single lumen CVC	Prolonged ileus following subtotal colectomy for large bowel volvulus	Surgery

[32] Gastrointestinal tract
[33] Central venous catheter

APPENDIX 5: Recruitment Procedure



APPENDIX 6: Participant invitation

This was sent as an A5 card

Invitation to take part in a Research Study

You have received this invitation because you have received intravenous nutrition (also known as TPN) while you were an inpatient at the University Hospital, Coventry.

A research study is being carried out looking at the patient experience of receiving TPN at the hospital to evaluate services and you are invited to take part. The study will involve taking part in an interview at a location of your choosing. More information is attached to help you decide whether you would like to take part.

Your contribution to this study would be greatly appreciated. If you would like to take part in this study or need further information please contact Joe Colby (Nutrition Specialist Nurse, UHCW Nutrition Team) on 02476 966074 or joe.colby@uhcw.nhs.uk

Thank you for considering taking part in this study

APPENDIX 7: Participant information sheet

University Hospitals Coventry and Warwickshire NHS Trust

University Hospital
Clifford Bridge Road
Walsgrave
Coventry
CV2 2DX

Tel: 024 7696 4000
Fax: 024 7696 6056
www.uhcw.nhs.uk

Participant information sheet

Title of Study: A phenomenological study exploring the patient experience of parenteral nutrition

I am inviting you to take part in a research study that is being carried out as part of a Professional Doctorate at Coventry University. Before you decide whether to take part it is important for you to understand why the research is being carried out and what it will involve. Please take your time to read the following information carefully and ask me if there is anything you are unsure about or if you need more information.

The purpose of this study is to develop an in-depth understanding of the experience of being a patient in hospital needing parenteral nutrition (also known as TPN). You have been invited to take part in this study as you have received parenteral nutrition when you were in hospital.

You do not have to take part in this study. If you choose to participate then you will be asked to sign a consent form. You will be free to withdraw from the study at anytime without giving any reason.

If you decide to take part in this study you will be asked to participate in an interview. This

will be arranged at a time and location of your choosing. The interviews are likely to take between 1-2 hours and will be audio-taped. Once the interview has been completed it will be written out in full and you will be asked if you would like to review the written copy to ensure you are happy that it represents the interview and amendments can be made if needed. The interview will then be analysed alongside other interviews to look for similarities and differences between the experiences.

Your name will not be used in the written transcripts and you will not be identifiable in any subsequent report. Only the researcher will have access to the recordings and transcripts which will be stored securely on password protected computers. If you choose to withdraw from the study after the interview none of the information you have given will be used in the study.

There are no payments available for taking part in the study but any expenses incurred due to your involvement in this study will be reimbursed e.g. parking.

Talking about a period when you experienced ill health can bring back bad memories. If this were to occur you would be able to terminate the interview at any time if you feel unhappy to continue and you can be put in touch with healthcare professionals to discuss your memories further if you wish. There are no other anticipated risks to taking part in this research. There are no obvious benefits to taking part in the study; however it will help guide future service developments which may benefit others in the future.

This study has been approved by Coventry University Ethical Approval Process and National Research Ethics Service (NRES) Committee Yorkshire & The Humber – Leeds West.

Researcher contact details: Nicky Wyer

nicky.wyer@uhcw.nhs.uk

02476 966144

If you choose to take part you will have a copy of this information sheet and a signed consent form to keep for your records.

Thank you for your interest in this study.

APPENDIX 8: Interview Topic Guide

- Introduction – purpose of interview, thanks for participation, clarification of TPN / PN terms
- Go through participant information sheet
- Consent x 2
- Pseudonym – any preferences
- Taking notes during interview

****TURN ON RECORDER****

- Tell me about yourself (introductory, ice breaker)

PARENTERAL NUTRITION

- The events that led to PN being required
    - How they would you describe what PN is – how it was explained to them
    - Why this type of treatment was needed
- Duration of PN
- How they felt at the time

EATING & DRINKING

- Were they able to take food or fluid by mouth? How it made them feel – emotionally, any physical symptoms
- What it was like restarting food and drink after not having them (if applicable)

LINES

- What it was like having a line for feeding
- What it was like having it inserted
- Who looked after the line?
- Was there more than one line, were they the same type of line

OVERALL CARE

- Who was involved in their care? What did they do?
- Any particular examples of the experience of care received (both good or bad)

- Has having PN affected them as a person?
- Any further information they want to add or discuss?

Thank participant for taking part

****TURN OFF RECORDER****

APPENDIX 9: Reflections from researcher diary

Extract from researcher diary, interview #6 with 'Susan' 27th May 2012

"Today I interviewed a lovely lady, however she was quite deaf which made the interview more difficult. I found that she struggled to catch some of what I asked and I needed to repeat and rephrase questions on numerous occasions. This was an interview where at some points I really struggled to get depth from the participant as well and it makes me reflect on the way that I ask questions. I have a tendency to ask questions using more words than are necessary, I must become more succinct. Even when I ask a succinct question I have a tendency to then ask a second question or to paraphrase the initial question without giving the participant opportunity to answer the appropriately succinct first version of the question.

I think today's interview has highlighted this issue to me as I made the interview more difficult with this style of questioning whereas in other interviews where hearing was not impaired it is possibly less of an issue. It was difficult to judge the impact of this as even when the participant clearly did hear the question her style of answering wasn't particularly in –depth even with several probing questions. As the interview went on my focus on having more succinct questions did help her to hear and understand the questions however the depth of answers was still a struggle to achieve on some of the areas of interest".

APPENDIX 10: Consent form

University Hospitals Coventry and Warwickshire NHS Trust

University Hospital
Clifford Bridge Road
Walsgrave
Coventry
CV2 2DX

Tel: 024 7696 4000
Fax: 024 7696 6056
www.uhcw.nhs.uk

Consent form

Title of study: **A phenomenological study exploring the patient experience of parenteral nutrition**

Name of researcher: **Nicky Wyer**

	Please initial box
1. I confirm that I have read and understand the information sheet dated 10/04/2012 (version 2) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.	
2. I understand that my participation in this study is voluntary and that I am free to withdraw at any time, without giving any reason without my medical care or legal rights being affected.	
3. I understand that data collected during the study may be looked at by individuals from Coventry University, from regulatory authorities or from the NHS Trust, where it is relevant to my taking part in this research. I give permission for these individuals to have access to my records.	
4. I agree to take part in the above study.	

Name of participant	Date	Signature
Name of researcher	Date	Signature

When completed: 1 copy for participant; 1 for researcher site file

APPENDIX 11: Coventry University Ethical Approval

Coventry University
Priory Street
Coventry CV1 5FB
Telephone 024 7688 7688

Professor Ian M Marshall

Coventry University

TO WHOM IT MAY CONCERN

RRU/Ethics/Sponsorlet

09 March 2012

Dear Sir/Madam

Researcher's name: Nicola Wyer
Project Title: A study exploring patient experiences of parenteral nutrition

The above named student has successfully completed the Coventry University Ethical Approval process for her project to proceed (ref: P4040).

I should like to confirm that Coventry University is happy to act as the sole sponsor for this student and attach details of our Public Liability Insurance documentation.

With kind regards

Yours faithfully

Professor Ian Marshall

Deputy Vice-Chancellor, Academic

Enc

APPENDIX 12: NRES Ethical Approval

NHS
Health Research Authority

NRES Committee Yorkshire & The Humber - Leeds West
First Floor
Millside
Mill Pond Lane
Leeds
LS6 4RA

Telephone: 0113 3050122
Facsimile: 0113 8556191

02 April 2012

Mrs Nicola J Wyer
Senior Specialist Dietitian - Nutrition Support
University Hospitals Coventry & Warwickshire NHS Trust
Department of Dietetics, 2nd Floor Rotunda
University Hospital, Clifford Bridge Road
Coventry
CV2 2DX

Dear Mrs Wyer

Study title: **A phenomenological study exploring patient experiences of parenteral nutrition in an acute teaching hospital**

REC reference: **12/YH/0185**

The Proportionate Review Sub-committee of the NRES Committee Yorkshire & The Humber - Leeds West reviewed the above application on 30 March 2012.

Ethical opinion

On behalf of the Committee, the sub-committee gave a favourable ethical opinion of the above research on the basis described in the application form, protocol and supporting documentation, subject to the conditions specified below.

Ethical review of research sites

The favourable opinion applies to all NHS sites taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" below).

Conditions of the favourable opinion

The favourable opinion is subject to the following conditions being met prior to the start of the study.

Management permission or approval must be obtained from each host organisation prior to the start of the study at the site concerned.

Management permission ("R&D approval") should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements.

Guidance on applying for NHS permission for research is available in the Integrated Research Application System or at http://www.rdforum.nhs.uk.

Where a NHS organisation's role in the study is limited to identifying and referring potential participants to research sites ("participant identification centre"), guidance should be sought from the R&D office on the information it requires to give permission for this activity.

For non-NHS sites, site management permission should be obtained in accordance with the procedures of the relevant host organisation.

Sponsors are not required to notify the Committee of approvals from host organisations.

1 The letter of invitation should be revised as follows:
- 'In order to improve services' should be replaced by ' to evaluate services'.
- The phrase 'as you have valuable experiences to share' should be deleted.

2 The participant information sheet should be revised as follows:
- It needs to explain in the opening paragraph that the study is for a PhD project.
- The final statement 'your participation would be greatly appreciated' should be deleted, it is coercive.

3 The consent form should follow NRES standard format, with boxes to initial and the mandatory section of access for regulatory authorities, information is available from www.nres.nhs.uk.

It is the responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).

You should notify the REC in writing once all conditions have been met (except for site approvals from host organisations) and provide copies of any revised documentation with updated version numbers. Confirmation should also be provided to host organisations together with relevant documentation.

Approved documents

The documents reviewed and approved were:

Document	*Version*	*Date*
Evidence of insurance or indemnity		01 August 2011
Interview Schedules/Topic Guides	1	02 January 2012
Investigator CV		18 March 2012
Letter from Sponsor		09 March 2012
Letter of invitation to participant	1	02 January 2012
Other: CV for Dr Merriman		
Other: Recruitment procedure	2	02 January 2012
Participant Consent Form	1	02 January 2012
Participant Information Sheet	1	02 January 2012
Protocol	2	02 January 2012
REC application		

Membership of the Proportionate Review Sub-Committee

The members of the Sub-Committee who took part in the review are listed on the attached sheet.

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

After ethical review

Reporting requirements

The attached document "After ethical review – guidance for researchers" gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Adding new sites and investigators
- Notification of serious breaches of the protocol
- Progress and safety reports
- Notifying the end of the study

The NRES website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

Feedback

You are invited to give your view of the service that you have received from the National Research Ethics Service and the application procedure. If you wish to make your views known please use the feedback form available on the website.

Further information is available at National Research Ethics Service website > After Review

12/YH/0185	**Please quote this number on all correspondence**

With the Committee's best wishes for the success of this project

Yours sincerely

Dr Rhona Bratt
pp **Chair**

Email: Elaine.hazell@nhs.net

Enclosures: *List of names and professions of members who took part in the review*

"After ethical review – guidance for researchers"

Copy to: *Professor. Ian Marshall, Coventry University*

Ms Ceri Jones, University Hospitals Coventry And Warwickshire NHS Trust

APPENDIX 13: UHCW Research and Development Department Approval

University Hospitals Coventry and Warwickshire NHS Trust

Research & Development Department
R&D Director: Prof. Chris Imray - Tel: 0247696 5222
Head of R&D: Ceri Jones - Tel: 0247696 6196
R&D Divisional Finance Manager: Chris Moore - Tel: 0247696 6198
Deputy R&D Divisional Finance Manager: Reena Savani - Tel: 02476 966199
Research & Development Business Manager: Natasha Wileman - Tel: 02476 966197
Research Associate: Isabella Petrie - Tel: 02476 966202
Research Associate: Claire Bacon - Tel: 02476 964995
Administration Specialist: Joanna Geraghty - Tel 02476 964995
Research Portfolio Development Manager: Deborah Griggs - Tel: 02476 96 6195

University Hospital
Clifford Bridge Road
Walsgrave
Coventry
CV2 2DX

Tel: 024 7696 4000
Fax: 024 7696 6056
www.uhcw.nhs.uk

18th April 2012

Mrs Nicola J Wyer
Senior Specialist Dietitian – Nutrition Support
University Hospitals Coventry and Warwickshire NHS Trust
Department of Dietetics, 2nd Floor Rotunda
University Hospital, Clifford Bridge Road
Coventry
CV2 2DX

Dear Mrs Wyer,

Re-Issued Approval Letter – Original letter dated 17th April 2012

Study Title: A phenomenological study exploring patient experiences of parenteral nutrition in an acute teaching hospital

Thank you for submitting the above study for consideration by the Research & Development Office. I am pleased to inform you that your study has been approved.

Approved documents
The documents approved for use in this study are:

Document	Version	Date
Protocol	2	02.01.2012
Participant Information Sheet	2	10.04.2012
Participant Consent Form	2	10.01.2012
Recruitment Procedure	2	02.01.2012
Letter of Invitation to Participant	2	10.04.2012

Conditions of Approval

- Should you wish to make any changes to the documents listed above, you must obtain R&D approval prior to use.

R&D Reference: NW103312
MREC Number: 12/YH/0185

- A Development Safety Update Report (DSUR) should be submitted to R&D. The first report is due on **the 18th April 2013** the DSUR replaced the Annual Safety Report (ASR) on 01 September 2011. Guidance on the DSUR can be found in SOP 5 'Regulatory Approvals and Communication' on the Trust R&D Intranet.

- Notification of any serious breaches of GCP or the trial protocol must be reported to the R&D Department and a DATIX Clinical Adverse Event form completed within 24 hours of any suspected breach being identified and confirmed.

Your research sponsorship & Indemnity is provided by Coventry University.

Your project may be subject to ad hoc audit by our department to ensure these standards are being met.

May I take this opportunity to remind you that, as a researcher, you must ensure that your research is conducted in a way that protects the dignity, rights, safety and well-being of participants. Trust R&D Approval assumes that you have read and understand the Research Governance Framework and accept that your responsibilities as a researcher are to comply with it, the Data Protection and Health & Safety Acts.

The Trust wishes you every success with your project.

Yours sincerely

Natasha Wileman
R&D Business Manager

Cc:
Ceri Jones, Head of Research & Development

Linda Merriman – Sponsor Representative – Coventry University

APPENDIX 14: A typology of bracketing (Gearing 2004: p1437-1438)

TABLE 2: Bracketing Compositions

	Bracket					
lement	*Ideal (Philosophical)*	*Descriptive (Eidetic)*	*Existential*	*Analytic*	*Reflexive (Cultural)*	*Pragmatic*
Abstract formulation	Positivism	Postpositivism, interpretative	Interpretative, critical	Empiricism	Constructivism, postmodernism	Variety
Orientation standpoint	Realism	Critical realism, relativism	Critical relativism	Relativism, constructivism	Relativism	Range of qualitative theories
Theoretical framework(s)	Descriptive phenomenology	Descriptive or Dutch (Utrecht) phenomenology qualitative theories	Existential phenomenology,	Ethnography, other qualitative theoris grounded theory	Hermeneutics, phenomenology,	Qualitative theories
Research praxis						
Foundational focus	Researcher sets aside suppositions; focuses in on immediate and universal	Researcher sets aside suppositions; focuses in on immediate	Researcher sets aside suppositions	Researcher sets aside some suppositions	Researcher sets aside some suppositions	Loosely defined, subject to interpretation
Internal (researcher) supposition	All held in abeyance	Most held in abeyance	Impossible to set all aside; some theories set aside	Most personal assumptions but not theoretical orientation set aside	Values, culture, and judgments identified and made transparent	Defined by researcher
External (phenomenon) supposition	All held in abeyance	Most held in abeyance	Impossible to set aside	Some (e.g., culture, institutions) set aside	Impossible to set aside	Defined by researcher
Temporal structure	Begins with investigation of phenomenon; ends when pure, raw description is attained	Begins and ends around specific phenomenon	Varied; bracketing established mainly to set aside theories	Unstructured; process repeated as required	Begins and ends during preparation; might return during analysis	Defined by researcher

(continued)

TABLE 2: (continued)

	Bracket					
Element	*Ideal (Philosophical)*	*Descriptive (Eidetic)*	*Existential*	*Analytic*	*Reflexive (Cultural)*	*Pragmatic*
Parenthesis (boundaries) composition	Ideal	Natural	Designed	Designed	Designed	Designed
Reintegration/ unbracketing and investment	Occurs after description of pure essences and structure of phenomenon; data reinvested to describeuniversals in lifeworld	Occurs after investigation of phenomenon; interpretation of data occurs after investigation	Affects research less because of boundaries; allows researcher to reinvest data	Continual process, with ongoing reintegration of data; interpretation remains iterative	Usually after identification of suppositions and attempt to minimize impact; suppositions might loosely remain	Most ill-defined component of bracketing; should be established prior to research
Foundations						
Developing founder(s)	Husserl, 1913/1931; 1970, 1999	Ashworth, 1996, 1999; Husserl; Pfander[a]; Spiegelberg, 1965, 1975, 1976	Merleau-Ponty, 1962, 1964, 1968; Jaspers, 1971; Kaufmann, 1989	Gubrium and Holstein, 1997, 1998	Many	Many
Philosophical foundation(s)	Brentano, 1874/1973; Descartes; Husserl[b]	Giorgi, 1970, 1971, 1985; Husserl; Pfander	Heidegger, 1962, 1972; Husserl; Scheler, 1970, 1973, 1980	Foucault, 1977, 1980; Garfinkel, 1967	Gadamer, 1965, 1967, 1981; Ricoeur, 1965, 1967; van Manen, 1995, 1997	Many

APPENDIX 15: Reflexive Bracketing (Gearing 2004: p1441)

Phase and Element	*Description*
Abstract formulation	
Orientation standpoint	Epistemology: constructivism, postmodernism Ontology: relativism
Theoretical framework(s)	Phenomenology, hermeneutics, grounded theory, other qualitative theories
Research praxis	
Foundational focus	Focus is to make transparent and apparent researcher's personal values, background, and culture suppositions; researcher identifies personal suppositions before investigation to minimize impact on phenomenon, attempts to bracket out, or at least identify, suppositions; impossible to focus in on or render phenomenon explicit
Internal (researcher) supposition	Researcher attempts to identify personal values, judgments, culture, and history; complete bracketing of personal assumptions is impossible
External (phenomenon) supposition	External suppositions not bracket out, as removal of context, culture, and environment is impossible; researcher wants to include larger world suppositions (e.g., culture) essential to phenomenon
Temporal structure	Preparation stage predominantly; can be included in analysis stage
Parenthesis (boundaries) composition	Designed; boundaries erected to reveal and identify researcher's suppositions to minimize interference; boundaries loose and porous
Reintegration/ unbracketing and investment	Generally occurs once researcher has identified suppositions and attempted to minimize impact; might loosely remain after investigation is complete and reinvested during analysis
Foundations	
Developing founder(s)	Many
Philosophical foundation(s)	Gadamer, 1975, 1976; Ricoeur, 1961, 1967, 1981; van Manen, 1995, 1997

APPENDIX 16: Examples of Reflexivity / Bracketing reflections

Bracketing interview 1st May 2012: My view of PN and the care provided by the hospital

I discovered from this interview that I was very clear that I felt every patient's experience of PN would be unique depending on the reason why they had IF and the journey that led them to require PN and that I was able to suggest areas of good and bad hospital care in relation to PN. Interestingly I did not have strong views on particular aspects being good or bad, rather, I could recognise instances when aspects of PN e.g. catheter insertion / care could be good or bad, which was encouraging to me that I was open to both positive and negative aspects of care. It became apparent that I was a strong supporter of the use of parenteral nutrition – but only in cases where its use was appropriate and of benefit to the patient. I found that through the discussion in the bracketing interview the patient was very much my focus, trying to get the service right for their needs and allowing their voice to be heard, which fits nicely with the methodological approach I have chosen for this research.

From being a core member of the NST I clearly had knowledge about PN and PN patients prior to this research. I knew what PN is, why it is used, the types of patients who require it and how to deal with the resulting problems associated with these types of nutritional problems, and although through this experience I was aware of the types of topics that may arise in the conversations with participant e.g. catheter, nursing, ability to eat I did not have any prior assumptions on what those experiences would be for the individual patient and, how they would impact on the patient experience. I also had no knowledge about the overall care experienced and

whether there were positive or negative aspects. I was able to recognise the uniqueness of every patients journey of PN and was open to the various experiences that may arise from the study.

Interview #8 with 'Mark' – 20th November 2013

Today's interview was very interesting with the information shared; it challenged me in a different way. The gentleman participating in the interview had required PN for a long duration in hospital and had been discharged on home parenteral nutrition. Unlike some of the earlier interviews, I had been involved, alongside the rest of the NST, in his care during his inpatient admission. What surprised me was the lack of information that he had retained in relation to why he required PN, what PN was and what we did as a team. This patient was reviewed frequently and lots of conversations were had regarding his treatment plan and what it all meant and from the NST point of view, we had felt that all the information had been conveyed appropriately and the patient had had sufficient opportunity to ask questions and discuss his treatment. I was rather surprised at some of the comments that were made during the interview today in relation to the questions

> *Nicky: So did you, did you know why you were fed over a longer period to begin with?*
>
> *M: No, I still don't know to this day why they fed me over twenty four hours, I haven't got a clue,*
>
> 'Mark' Interview 8 page 9, lines 5-6

> *M: You know, because I have that bloody thing err, four times a week that clear one [PN bag], no, Tuesdays, no Mondays, Christ what day is it, Thursday, Friday, I have it Tuesday, Thursdays, Fridays and Sundays, that's, other than that I have the others, the err, fat bags, in between*
>
> *Nicky: And do you know why you have different bags?*

M: Ain't got a clue, that is something that I don't know

Nicky: Yeah

M: Well, what is the difference?

Nicky: I'll, I'll talk to you about some of these things after the interview

'Mark' Interview 8 page 15, lines 15-22

These comments challenged me as they made me feel defensive regarding the actions of the team. However, I focused on remaining neutral and not commenting on the points he made, rather to probe further to illuminate his viewpoint. I made a couple of notes on my pad to remind myself of the topics so that after the interview I could do a debrief for the participant as there were important things that he should understand about his treatment. At one point when he asked me a direct question, I did state that I would come back to his queries after the interview - which I did. This was a huge learning point for me as a member of the NST – just because we think we have told a patient something or discussed an aspect doesn't mean that they understand it or retain it and I suspect that in the inpatient environment this is made harder as the patients are not feeling well and are frequently visited by different teams so the messages can get lost or confused. However, in terms of the interview I feel good that I was able to remain focused and neutral in my questioning and to allow the content and direction of the interview to remain patient focused. This is an example of where my own knowledge and beliefs was set aside from the matter at hand – the patient being interviewed and their experience.

Post data collection reflection – 20th June 2014

During data collection I focused on adopting the phenomenological attitude, maintaining openness to the narrative of the participant. However in several of the

interviews the participant, knowing that I worked as part of the nutrition support team, asked questions regarding their experience, for example:

> *M: I don't really know, I, I can't remember if they told me but the little bubbles, they're not so bad, but I don't, what would happen? Do you know?*
>
> *Researcher: We'll talk about it after the interview [laughs], I'll make a note of it*
>
> *M: [Laughs]*
>
> 'Mark' Interview 8 page 18, lines 12-15

This challenged my phenomenological attitude, as I felt that it was important, as a clinician, to acknowledge these questions and to provide answers. I addressed this by instead taking notes of items to "debrief" the participant about after the interview had been completed.

Appendix 17: Colaizzi's Method of Phenomenological Data Analysis (1978)

Step 1

The transcripts are read in-depth to obtain a feel for the data, its inherent meaning.

Step 2

Significant statements or phrases are extracted

Step 3

The meanings of each statement are then formulated

Step 4

The formulated meanings are organised into clusters of themes revealing patterns in the data. During this time the original transcripts are reviewed and compared to ensure validation

Step 5

The results are then integrated into an exhaustive description of the phenomena in question.

Step 6

The exhaustive description is formulated into a statement of identification of its fundamental structure i.e. the essential structure of the phenomenon

Step 7

Participants are revisited and asked about their views of the findings so far.

Appendix 18: Interview 7 with 'Sunita' highlighting significant statements from the transcript and addition of researcher comments

In this section of text significant statements were highlighted in green and comments relating to the text made by the researcher during transcription are indicated in red.

S: I don't think the eating was an issue because I was on the TPN, it used to be annoying though having to have that, lugging it around, [Lack of oral diet not a concern as reassured as having PN. Annoying being attached to PN. Cumbersome] and, at night having to go to the loo, because my sister used to have a mattress there so before I would get up I'd have to say "[sister] get up" and she would have to get up and we had a little routine where she'd get up, lift it up and I'd have to run round and then I would go to the loo and she would wait there until I came back out and then she would put her mattress back down. Every night, because I used to have to go to the loo about four times during the night because of all this liquid that I was having [Sleep disturbances. Nocturnal urination] and then they would have to help me bathe and stuff like that as well, and I used to hate it and then all the tubes on me and then I think because that was when I was having it during the day and then it got, they said they were going to change it so I wouldn't have in during the day and I would just have it in the evenings [Hated being attached to the PN - restrictive. PN hours changed 'they' changed it ?in response to patient views]

Nicky: Do you know why that was? Was that explained to you?

S: Yeah, I think they said that they wanted to, err, lower the, they wanted to, for me to be mobile during the day and not have this with me and erm, it was just so that I could be free during the day because I used to hate having to have that stand next to me and always be walking about with it and I wasn't allowed out of the ward, wasn't allowed outside which I hadn't been outside by this time for about three or four months [PN hours reduced to allow for greater mobilisation. Freedom. Greater normality without PN attached] and err, I think that was it, yeah

Nicky: So was that a positive thing for you then sort of having, being attached to it for less time because of what you've said?

S: Yeah, definitely, and err, I used to, I used to hate having to see people, see me with it, 'cause it, it made it, me look like I was really frail and ill [PN associated with

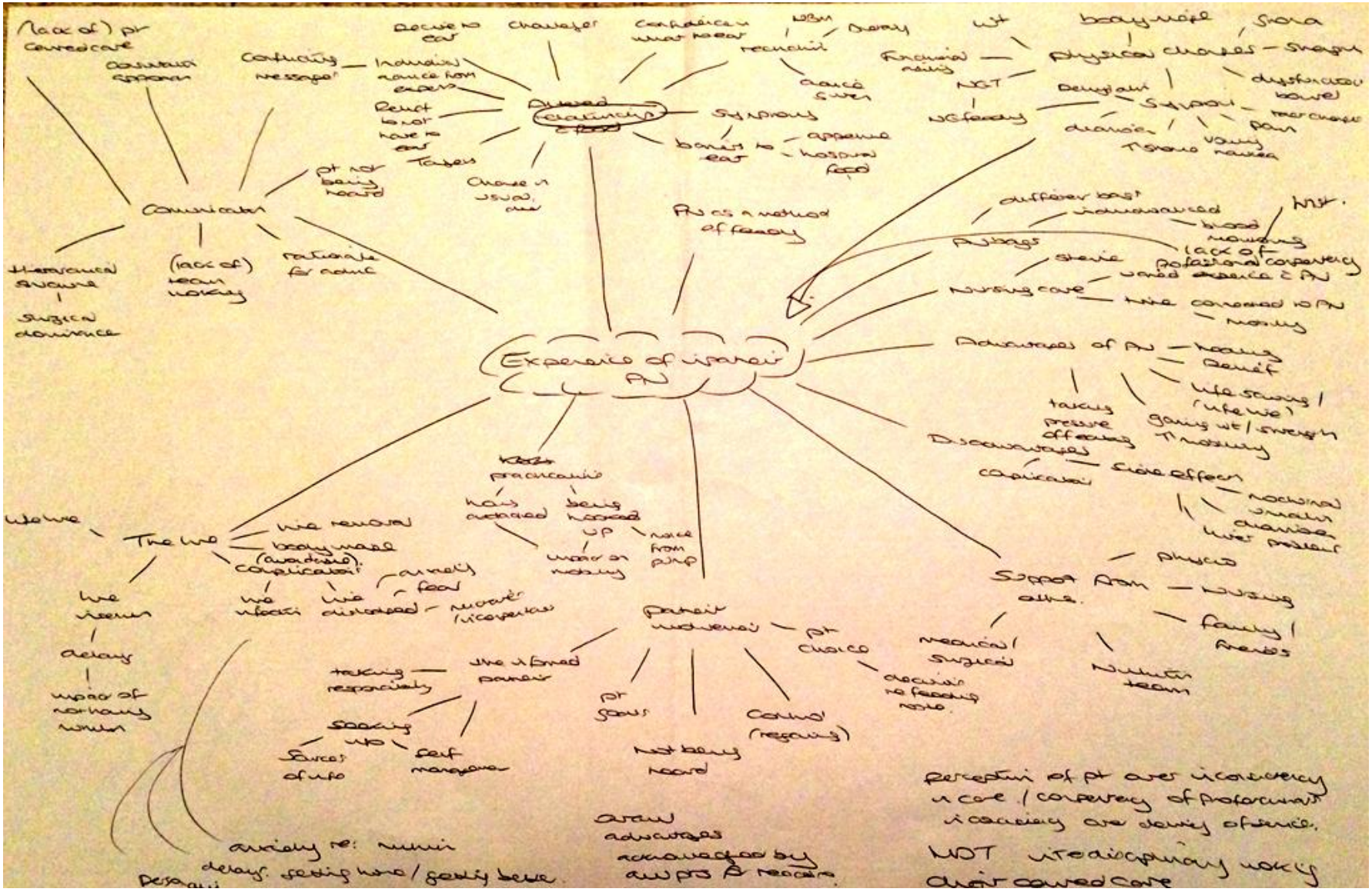
frailty and illness. Social impact of illness / PN] so erm, I used to always say, oh can I have it after my visiting time is over [laughs] 'cause my friend when she used to come and see me and I used to say can I have it after they go can I have it on, and then when they used to come I used to pretend there was nothing wrong with me [Hiding PN from visitors. Social impact of being attached to PN. Desire for normality in front of friends] and, but there's a couple of friends that knew, the seriousness of what happened, because I didn't explain it to everyone, what I was having done and what had happened, so, they used to come I'd say they're fine, just being overprotective and they won't let me go home, but really as soon as they went they would have to come and put the TPN on [adjusting the PN connection time to fit in with patient preferences] and I'd have it and then gradually I started noticing that my strength was coming back 'cause I was able to do things on my own, be a lot more mobile, walk about, 'cause I think initially at the beginning I wasn't able to move, walk about on my own or anything [improvements in strength and functional ability. Noticing positive changes. Feeling that PN is working]

Appendix 19: Significant statements and formulated meanings – examples from Interview 7 with 'Sunita'

Significant statements	Formulated meanings
I don't think the eating was an issue because I was on the TPN, / it used to be annoying though having to have that, lugging it around, and, at night having to go to the loo, because my sister used to have a mattress there so before I would get up I'd have to say "[sister] get up" and she would have to get up and we had a little routine where she'd get up, lift it up and I'd have to run round and then I would go to the loo and she would wait there until I came back out and then she would put her mattress back down. Every night, because I used to have to go to the loo about four times during the night because of all this liquid that I was having (7.11.1-7)	7.43 Whilst on PN eating was not a concern 7.44 Mobilising with PN was annoying 7.45 Frequent nocturnal urination on PN
I used to hate it and then all the tubes on me and then I think because that was when I was having it during the day and then it got, they said they were going to change it so I wouldn't have in during the day and I would just have it in the evenings (7.11.8-10)	7.46 Being attached to the PN was frustrating 7.47 The PN was modified so it was just given during the evenings
Yeah, I think they said that they wanted to, err, lower the, they wanted to, for me to be mobile during the day and not have this with me and erm, it was just so that I could be free during the day because I used to hate having to have	7.48 PN was stopped during the day to encourage mobilisation

that stand next to me and always be walking about with it and I wasn't allowed out of the ward, wasn't allowed outside which I hadn't been outside by this time for about three or four months (7.11.12-16)	
I used to hate having to see people, see me with it, 'cause it, it made it, me look like I was really frail and ill (7.11.19-20)	7.49 PN affected the sense of self, bringing feelings of frailty and illness, anxiety was also felt regarding how others would perceive this
Can I have it after they go can I have it on, and then when they used to come I used to pretend there was nothing wrong with me (7.11.22-23)	7.50 Nursing staff were liaised with to agree that PN would be attached after visiting to reduce patient anxiety over her changed sense of self and health status
Gradually I started noticing that my strength was coming back 'cause I was able to do things on my own, be a lot more mobile, walk about, 'cause I think initially at the beginning I wasn't able to move, walk about on my own or anything (7.11.27-29)	7.51 Strength improving on PN 7.52 Becoming more mobile and independent
Slowly, having the TPN over like, I think over about a month then I noticed that my strength was coming back, I was feeling a lot better in myself and yeah....so that was good, positive (7.11.31-33)	7.53 Strength improving on PN after a month 7.54 Psychological improvements on PN

Appendix 20: Initial Concept Map

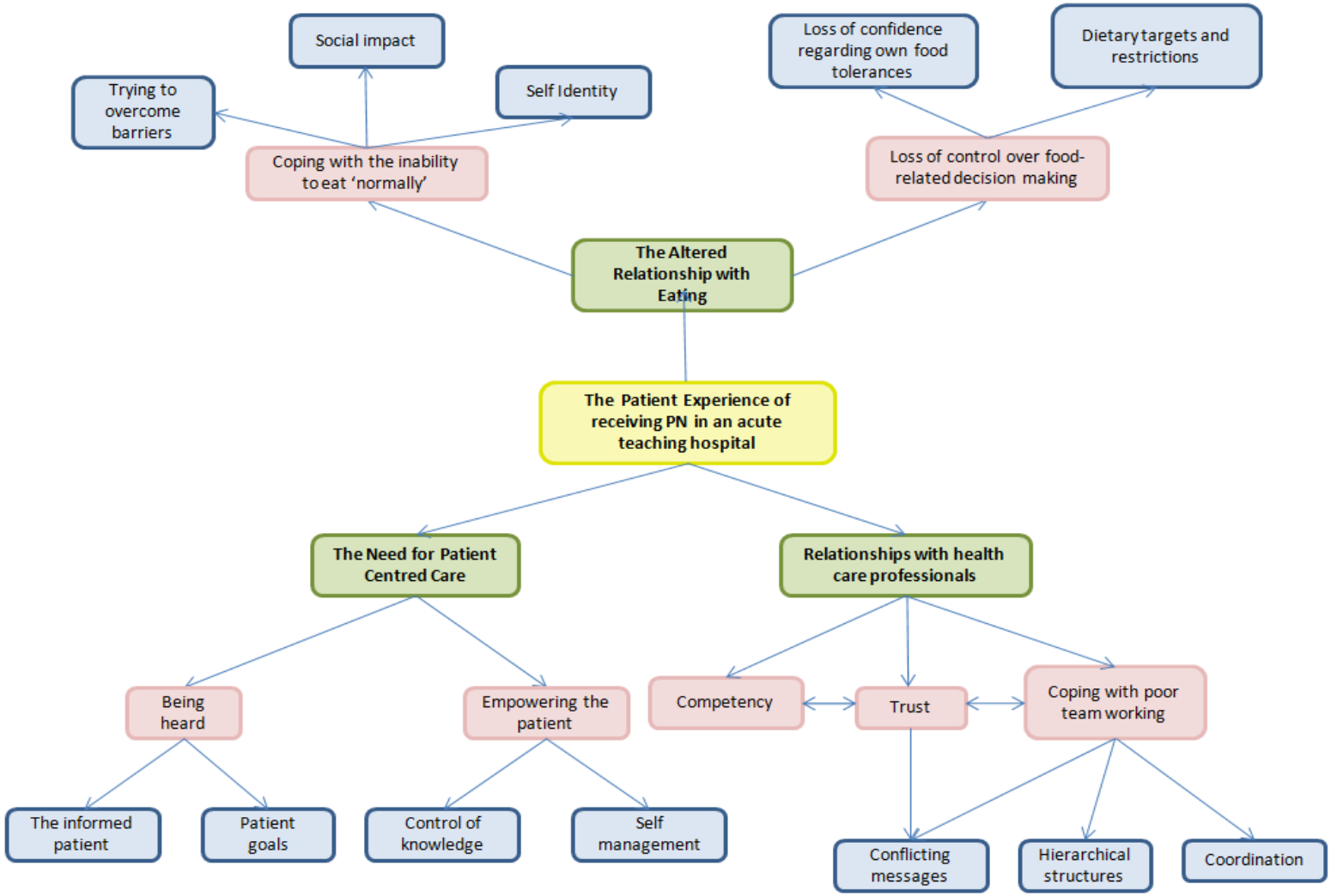

Experience of inserting PN
Communication
The NG
Patient involvement
Support from others
Advantages of PN
Disadvantages of PN
PN as a method of feeding
Altered relationship with food
Knowledge/practicalities
Lack of (PT) choice
Lack of professional competency
Lack of NG tube care
Lack of PN care
Lack of support
Lack of time
Lack of time to eat
Lack of time to prepare food
Lack of time to eat food
Lack of time to prepare food
Lack of time to eat food
Lack of time to prepare food
Lack of time to eat food

Appendix 21: Imaginative variation during formation of themes

Examples of some of the questions asked of the data to help determine the overarching themes and subthemes:

- Were all participants nil by mouth whilst on PN? No
- Were all participants able to eat whilst on PN? No
- Did participants want to eat whilst on PN? Varied
- Did all participants have an altered relationship with food? Yes
- Those who were able to eat, did they eat according to their usual diet? No
- Did participants have control over their eating? Varied, mainly no
- Was there advice given on what to eat? Yes
- Was the advice clear for the participants? No – mixed messages, conflict
- Did eating have consequences for the patients? Yes – symptoms
- Did the ability to eat affect the provision of PN? Yes in some
- Did all participants want to be involved in their care? Yes
- Did participants feel that they had experienced patient centred care? Varied
- Did all participants feel the relationship with healthcare professionals during the period of receiving PN was important? Yes
- Did the relationship between the patient and the HCPs affect the overall experience of receiving PN? Yes
- Is PN defined by the presence of an intravenous feeding device? Yes
- Is the experience of having a line determined by other factors? Yes – support, advice etc

Appendix 22: Final Concept Map



Appendix 23: Dissemination Plan

- Abstract and poster presentation – digestive disorders federation conference 22nd-25th June 2015 - **Completed**
- Poster presentation – UHCW Research, Development and Innovation Conference 3rd July 2015 - **Completed**
- Presentation at UHCW dietetic department continuing professional development (CPD) meeting
    - 20th May 2015 - **Completed**
    - 21st October 2015 - **Completed**
- Presentation and facilitation of group work exercises at UHCW Nutrition Support Team annual team building day 15th July 2015 - **Completed**
- Article submission to the Journal of Human Nutrition and Dietetics – **Plan to submit by March 2016**

Appendix 24: Abstract submission for Digestive Disorders Federation Conference 22nd – 25th June 2015

Appendix 25: Poster presentation - Digestive Disorders Federation Conference 22nd – 25th June 2015

Appendix 26: Poster presentation – UHCW Research, Development and Innovation Conference 3rd July 2015

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